CROHN'S & COLITIS UK

FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER

LIVING WITH CROHN'S OR COLITIS

YOUR GUIDE

ABOUT THIS BOOKLET

Living with Crohn's or Colitis will mean you have to make some changes. But you can still get the most out of life. And we're here to help, every step of the way.

This booklet looks at some of the situations you might face when dealing with your condition day-to-day. It contains ideas and suggestions based on the experiences of people with Crohn's and Colitis and the advice of professionals.

We write our publications together with people affected by Crohn's and Colitis, health professionals and other experts. The content is based on up-to-date, unbiased, evidence-based research. We don't recommend any particular products, and this information isn't meant to replace medical advice. Please speak to your GP or IBD team before making significant changes to your lifestyle.

Email publications@crohnsandcolitis.org.uk for a list of research used to inform this booklet, for details of conflicts of interest or if you have any feedback on our publications.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This publication is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit **crohnsandcolitis.org.uk**

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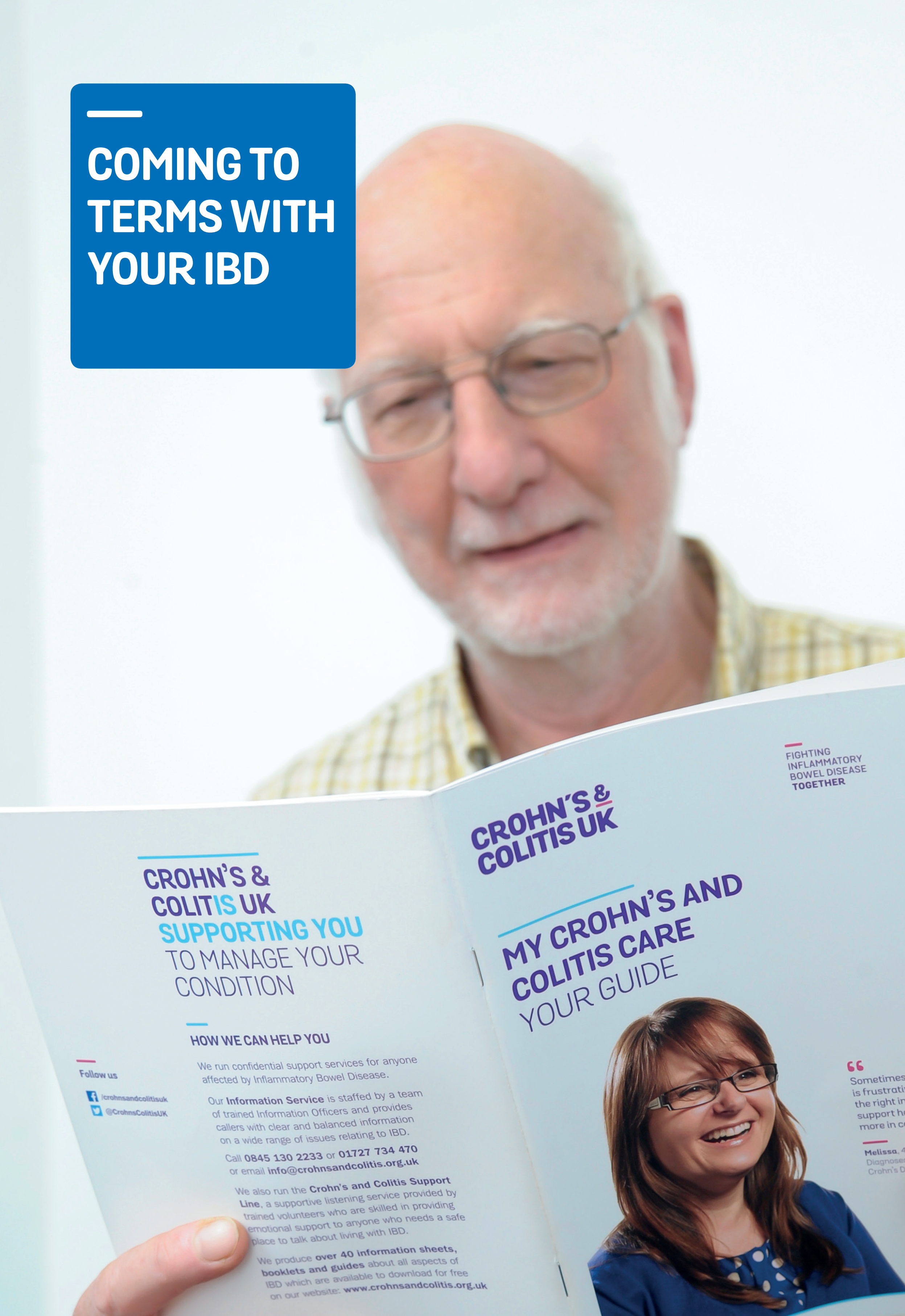
COMING TO TERMS WITH YOUR IBD



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LIVING WITH INFLAMMATORY BOWEL DISEASE

The two main forms of IBD are Crohn's Disease and Ulcerative Colitis. Living with these conditions can come with many challenges.

In both Crohn's and Colitis, parts of the digestive system become swollen, inflamed and ulcerated. This usually occurs in the intestines, also known as the gut or the bowels. Common symptoms include pain, diarrhoea that sometimes contains blood and mucus, weight loss and tiredness. Some people develop anaemia or have problems with their joints, skin and eyes.

IBD is a chronic condition, meaning it is long-term and there is no known cure at present. IBD can flare up unpredictably, although you may also have long periods of good health when the condition is in remission. Research, including work funded by Crohn's and Colitis UK, is continuing to improve people's quality of life and to eventually find a cure. Visit **www.crohnsandcolitis.org.uk/research** to find out more.

> “I missed my uni finals, and my planned wedding, and thought the end of the world had come. It hadn't. Good things have come along, and good people. There will be losses, changes of direction, but different is not always worse. It's different.”
>
> **Denise**, age 69, diagnosed with Crohn's Disease in her early 20s

HOW YOU MAY FEEL AT FIRST

As well as having to deal with physical symptoms like pain, diarrhoea and fatigue, you also have to deal with your emotional reactions. Being diagnosed with a long-term and potentially embarrassing illness like IBD can trigger a range of emotions. After feeling unwell for quite a while, people may react to their diagnosis with a mixture of shock, depression, anxiety and relief.

You may also feel confused and uncertain about what to expect. After all, you may not have heard of IBD before. So it's natural to feel concerned, particularly when medical science doesn't yet know the actual cause of the illness.

It can often be a relief to find that your symptoms have an identifiable name and can usually be controlled with medication, although surgery may sometimes be necessary.

It may also help to know that you are not alone. More than 300,000 people in the UK have Ulcerative Colitis or Crohn's Disease and many find it helpful to talk to others who have been in a similar situation. See Finding a local community to learn how you can connect with others and get involved.

YOUR FEELINGS LATER ON

The ongoing and unpredictable nature of the disease can be especially difficult to deal with. Just when you think you have come to terms with your IBD and are beginning to get on top of it, there may be new situations to tackle. It can all seem so unfair.

For example, you may suddenly have a worse flare-up than before, or start getting unpleasant side effects that are difficult to manage. If your medication is not working as well as had been hoped, your doctors might recommend surgery.

More positively, you may discover that a new drug works better and helps to keep you in remission for much longer than before. Or you may find that following surgery, your most troublesome symptoms have disappeared.

Some people find they feel more in control if they learn all they can about their condition and how to manage it. Your IBD team is there to answer any questions you have. The amount of detail you wish to have is entirely up to you. Crohn's & Colitis UK also has a confidential helpline and a range of publications that explore various aspects of IBD, available at www.crohnsandcolitis.org.uk. See the **How we can help you section** at the end of this booklet for more details.

> "I have found that I needed to know as much as I could about my condition, which has enabled me to make informed decisions with my medical team, and also – five years on – be able to deal with it better."
>
> **Carol**, age 53, diagnosed with Crohn's Disease in 2012

HOW YOU SEE YOURSELF

It is natural to feel upset and even angry about being diagnosed with IBD, and some people initially respond by being in denial. While it is not easy coming to terms with an illness, accepting that you have a medical condition, and that there may be times when you have to take things more easily, can help you to keep a balance in your life.

Many people with IBD are able to live life to the full, doing well in their studies, jobs and personal pursuits. When you have a flare-up, however, you may need to make adjustments and take time to recuperate. People living with IBD can sometimes feel guilty, or that they are making a fuss over nothing, if they need to rest or take time off work or education.

“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 Ulcerative Colitis in 2007

Remember that you are living with an ongoing and challenging illness, and, understandably, there may be times when you feel low, anxious and tired. When this happens it is really important that you take care of yourself and rest as much as you need.

When you aren’t able to do all the things you might like to, that doesn’t mean you’re not coping. It probably means you’re doing very well in a difficult situation. You may find that living with a chronic illness allows you to discover alternative ways to achieve your goals.

TAKING CARE OF YOURSELF

Living with IBD brings many challenges, and often causes a great deal of stress. Stress is not regarded as a cause of IBD, but too much is not good for anyone, especially someone dealing with an ongoing condition. So it is important to look after yourself as best as you can.

Becoming aware of the cause of your stress is often the first step in tackling it. You may be able to avoid some stressful situations or, if not, make plans for how to deal with them. You may find these tips beneficial for reducing stress:

- Understand how your energy is affected by your IBD and be realistic about what you can achieve. It is okay to say ‘no’ if you feel you are taking on too much.
- Make time for relaxation or leisure each day by doing something you enjoy that helps you unwind. Some people find that exercises such as deep breathing, deep muscle relaxation, meditation or yoga help them feel more able to cope with the daily stresses of living with IBD. 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 if you can.
- Try to get some form of regular exercise. See **Exercise and Sport** below.
- If possible, take regular breaks. Just a brief change of surroundings can be as good as a longer holiday.
- Some people find it beneficial to talk things over with someone they can trust and share their feelings with. Writing down your feelings in a journal or blog, or visiting a supportive web forum, can also help. See the **Finding a local community** section in this booklet for information on Crohn’s and Colitis UK’s closed Facebook forum.

> “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

Many people with IBD occasionally experience periods of feeling worried or depressed. It is important to remember that these feelings are not irrational or a sign of weakness. If you find the stress of your illness is having a considerable impact on your life and emotional well-being, you may find it helpful to talk to a counsellor. Some people with IBD have found that their stress levels are reduced after counselling, which led to improvements in their IBD symptoms as well as their psychological well-being.

There may be a counsellor available through your GP practice, or you could ask the IBD team or social worker at your hospital. Our information sheet **Counselling and IBD** has more information about how counselling may help you, and how to find a counsellor.

TALKING TO OTHERS ABOUT YOUR CROHN'S OR COLITIS

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HOW OTHER PEOPLE SEE YOU

People with IBD often feel that those around them, even close family or friends, don't seem to understand what it means to have Crohn's or Ulcerative Colitis. There is a general lack of awareness of IBD, and if you know very little about an illness, it is not easy to imagine what it must feel like. Even when people are informed, it is still not the same as having the condition.

Sometimes people's reactions can be difficult to manage and may even be hurtful. They may desperately want you to be well, which can put pressure 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 dismiss some of your symptoms as unimportant. Just as you have to come to terms with the diagnosis, it can take time for those around you to learn and to adjust.

You may find that some people will blame your personality for the condition. "Oh, obviously you've got it because you're such a worrier," they may say. This can be upsetting, and difficult to argue against when there isn't a clear, scientific explanation of the cause of IBD. This situation is not helped by the common perception that anxiety, fear and stress can have adverse effects on people's general health, particularly on their bowels. But there is no evidence that IBD is caused by stress, although it can be stressful to have IBD, and stress may, in some cases, be a factor in causing flare-ups.

Being told what to feel can also be irritating. People 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. Such suggestions may be annoying even when they are offered with the best of intentions. While it can feel like they are minimising your condition, try not to let these things take over, Instead, put it down to a lack of understanding.

Sometimes people may claim that they, too, suffer from IBD, when what they are describing are occasional 'tummy complaints' that they have for a few days at a time. It can also be very difficult for other people to understand what 'urgency' to use the toilet means. Friends may say, "But surely you can hang on for a couple of minutes?", with no idea that you simply can't.

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HELPING FAMILY AND FRIENDS UNDERSTAND

You may find that if you tell your family and friends at least something about your illness, they will feel reassured and more able to give you the kind of support you would like. It may help you to feel more in control of the situation and less anxious about your symptoms and treatment. It can also help them to feel included and less helpless.

It is worth bearing in mind that other people's reactions to your illness will be affected by their own personalities and experiences – and that some adverse reactions may be prompted by their own fear rather than lack of sympathy.

Symptoms of IBD can be embarrassing for some, as we tend not to discuss bodily waste, toilets and bowels, even with people we're close to. 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 family and friends to read about it. Our information sheet on **Supporting Someone with IBD: A Guide For Friends and Family** has lots of helpful tips for loved ones to help them understand and support you.

> “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

Another way to help someone close to you understand your illness is to ask your doctor if they will explain it to them. This can be particularly useful if you need to give the information greater authority or reassurance.

You can probably best help people to understand by being open and clear about how your condition affects you, and by saying how they might be most helpful. It can be useful to find someone with whom you feel comfortable to 'practice' talking about your condition to become more confident about it.

With some people you may not want to go into detail. You could just say something like: "I have a gut condition that means I have to rush to the toilet very suddenly" or "I have an illness that means I get tired very easily, so I have to pace myself." Many people will accept this type of explanation and not question you further.

If you are a parent with IBD, you may be concerned about talking to your children about your condition. We have an information sheet on **Talking to my child about my IBD** that may help you decide whether to talk to your children about your condition, and ways you could approach it.

WHAT TO SAY AT WORK

There is generally no legal requirement to disclose a medical condition unless asked to do so in your personal contract of employment. 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.

Be open about your IBD

Some people worry that it might be risky to tell their employers about their IBD. However, trying to hide symptoms at work can be a strain and you may find it a relief to talk about your IBD. In some circumstances, your employer may have a duty to make what are known as ‘reasonable adjustments’ for you. These could include, for example, moving your desk to an area nearer the toilets, arranging a more convenient parking place, or perhaps even different working hours.

If you can, being open about your IBD with your colleagues may also make it easier to cope with your condition at work. If everyone knows the situation, you won’t feel the need to avoid being seen taking your tablets or to make excuses about tummy upsets. Explaining that it is not infectious is always worthwhile – people often worry about this but don’t like to ask.

On a more practical level, make sure you know your workplace’s policy on sick pay and time off for medical appointments. 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) or Universal Credit. You can find more information on this and other benefits, together with details of helpful organisations, on our website or by ringing our helpline. Contact details are given at the end of this booklet.

WHAT TO SAY AT SCHOOL OR UNIVERSITY

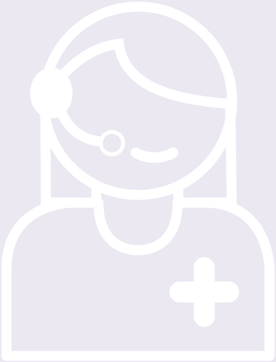
You do not have to tell anyone about your IBD if you do not wish to. However, letting your school, college or university know about your condition will mean you are more likely to receive the help and support that is available. For example, you could be given extra meal breaks, extensions on deadlines when you are unwell, or permission to sit close to the door in order to leave class discreetly if you need to rush to the toilet. It may help to give your department a copy of our information sheets **Students with IBD: A guide for universities and colleges** or **Children and Young People with IBD: A guide for schools**, which include basic information on IBD and suggestions for support.

Some people worry about telling their peers about their condition. You may fear being ridiculed for having to rush to the toilet, having ‘an accident’, or creating noises or smells. 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 are 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 that IBD can cause.

Our information sheet **Students with IBD: A guide for students** has some suggestions on how to discuss your condition with your department as well as with other students.

Crohn’s & Colitis UK also has a series of videos featuring young people with IBD sharing how they dealt with transition, relationships, working and going to school. These are available at **www.crohnsandcolitis.org.uk/young-person.**

> “I have found telling tutors and friends has been really helpful. On days when I feel ill or tired, they are supportive and usually try and find a way to lift my spirits.”
>
> **Isobel**, age 22
> diagnosed with Crohn’s Disease in 2012



TALKING TO YOUR DOCTOR OR NURSE

Having IBD means that you are likely to visit your GP and consultant more often than you did before you were ill. You may also have regular appointments with the hospital IBD team. It can be helpful if you are able to build up a good relationship with them.

Being open and frank about your symptoms and your needs will make it easier for your doctors and nurses to make sure you get the right treatment. Taking a more active role, learning about your condition and talking it through with your healthcare team can also make you feel more confident about managing your IBD.

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. The more honest and direct you are, the more your doctors and nurses can help you.

Some words you might find useful when talking to the doctor or nurse are ‘motion’, ‘stool’ or ‘bowel movement’. But they have heard 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 separate hard lumps, lumpy and sausage-like, soft blobs, liquid - or other descriptions. Other words and phrases you might find useful are ‘urgency’, ‘having an accident’, ‘afraid I won’t get to the loo in time’, ‘explosive diarrhoea’, ‘gas’, ‘flatulence’ or ‘wind’.

These are just suggestions – thinking of your own descriptions in advance can help you better inform your health professionals so they can help you, and may save possible embarrassment.

Your doctors or nurses will be expecting you to have questions, so don’t be afraid to ask all you want to know. If something isn’t clear, ask them to explain it.

Don’t be afraid to ask questions

It can also be helpful to:

- Make a list of the important questions you want to ask, as well as any changes in your symptoms, and take it with you to your appointment.
- Jot down the answers to your questions while you are there – perhaps on your list.
- Take a friend or family member with you, as they can remind you what was said.

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 flare, which could include adjusting your medication. Taking an active role in your medical care can also help you feel more in control.

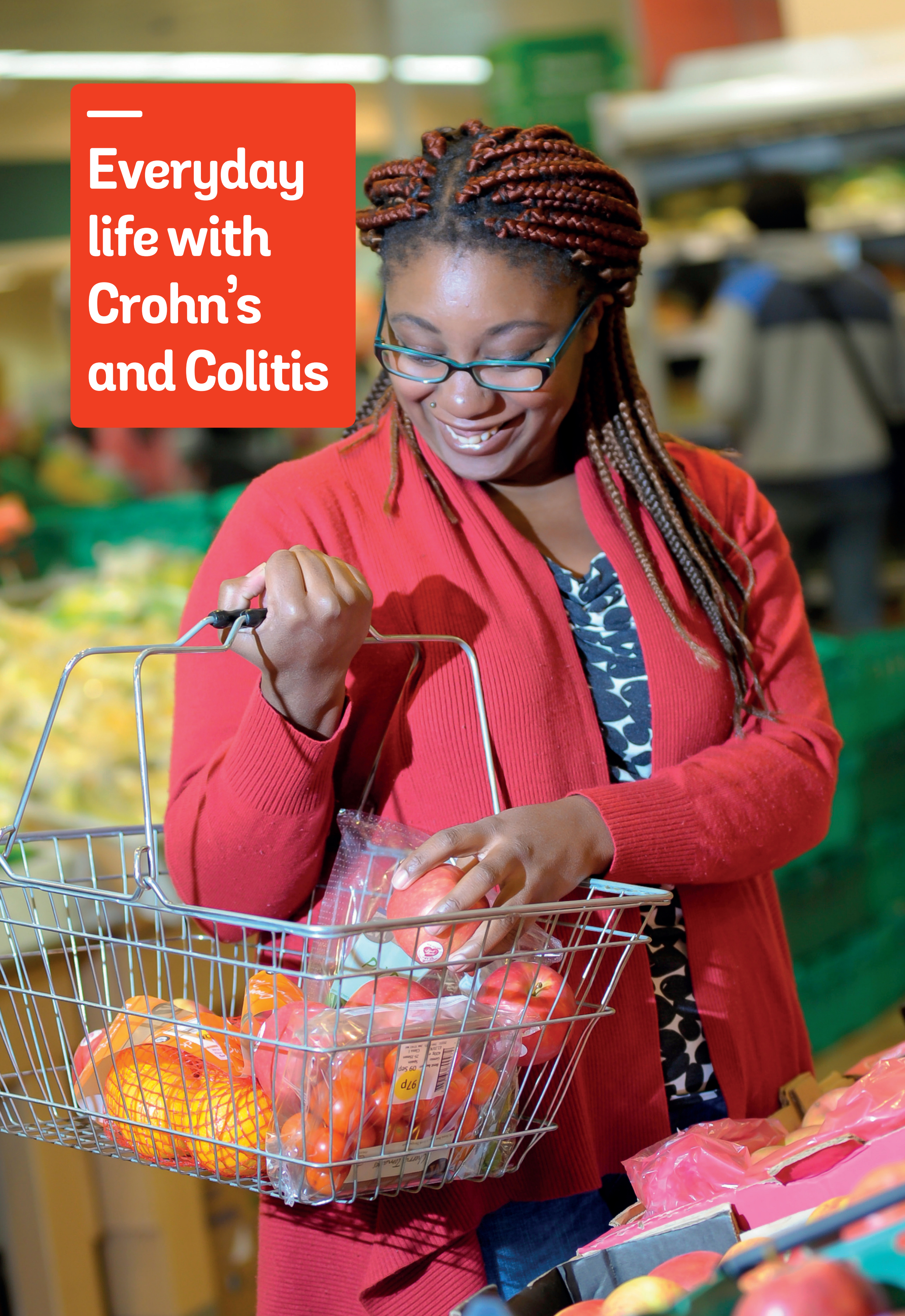
Some IBD teams have an IBD nurse helpline to call if you have questions or your symptoms change. You should ask your team what procedure you should follow when you have questions or notice a change in your condition. A good rule of thumb is that if something is occurring that isn’t normal for you, contact your GP or your IBD team.

We offer other publications, such as our individual drug treatment leaflets, which give more information about the different medications available to treat Crohn’s and Ulcerative Colitis. We also produce two leaflets on **surgery for IBD**.

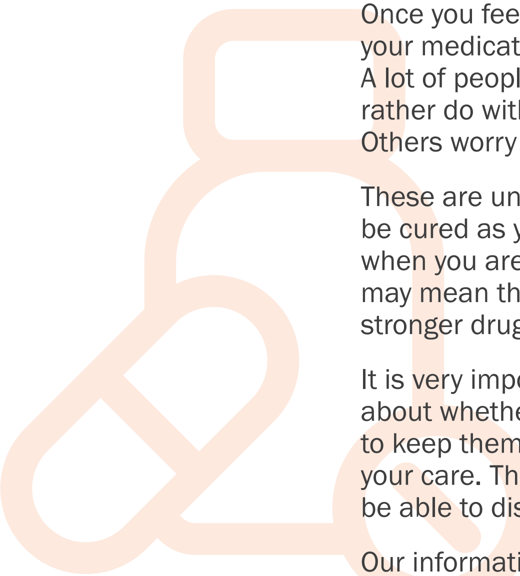
If you are a young person living with IBD, you will eventually move from a children’s to an adult IBD team. Our **Transition: Moving to adult care** guide has details on how to work with your doctors and nurses to make the process as smooth as possible.

Our videos featuring young people with IBD sharing how they dealt with transition and other issues are available at **www.crohnsandcolitis.org.uk/young-person.**

Everyday life with Crohn's and Colitis



TAKING MEDICATION



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 anymore. A lot of people become fed up taking pills and would rather do without daily reminders of their condition. Others worry about side effects from their medication.

These are understandable concerns, but as IBD cannot be cured as yet, continuing to take medication even when you are well reduces the chance of a flare-up, and may mean that you are less likely to need additional stronger drugs.

It is very important to be honest with your IBD team about whether you are taking your medicines, as failing to keep them informed could have a negative effect on your care. They will understand your concerns and may be able to discuss alternatives.

Our information sheet **Taking Medicines** looks at some of the most common questions and concerns about IBD drugs.

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 variety out there – homeopathy, acupuncture, aromatherapy, hypnotherapy, herbal remedies, special diets, relaxation techniques – to name but a few. Some are presented as alternatives to traditional medical treatment. Others say they are ‘complementary’, which means they may help you in addition to the treatment you are already receiving.

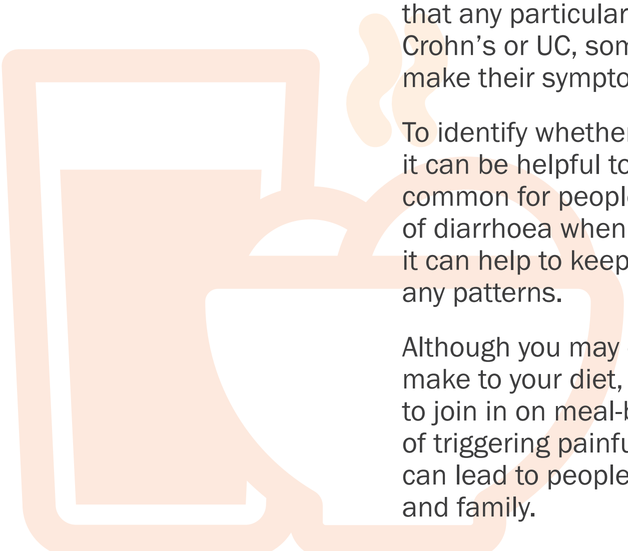
Many of these approaches are still being researched, and although they may help some people, there is no conclusive evidence about when, how or whether they will work. What may help one person may not work, or even have a harmful effect, on another.

Small studies have shown that acupuncture and a herbal medicine containing wormwood may help with Crohn's Disease, but more work is needed in this area. Research also suggests that certain varieties of high-potency probiotics may help maintain remission in people with UC, although evidence for this is inconclusive. For more information see our booklets **Ulcerative Colitis** and **Crohn's Disease**, and our information sheet on **Other Treatments for IBD**.

If you do decide to try any of these approaches, discuss it with your doctor first. In particular, don't give up the medication you are on, and don't take any new therapies including herbal remedies, go on an extreme diet, or have procedures like colonic irrigation, without talking to your IBD team.

DIET AND IBD

You may find that your relationship with food changes once you have IBD. While there is no clear evidence that any particular food or food additive causes Crohn's or UC, some people find that certain foods make their symptoms worse.



To identify whether any foods set off your symptoms, it can be helpful to keep a food diary. For example, it's common for people with IBD to experience a worsening of diarrhoea when they eat spicy or high-fibre foods, so it can help to keep track of what you are eating to note any patterns.

Although you may discover helpful alterations you can make to your diet, many people can then find it difficult to join in on meal-based social occasions, due to fear of triggering painful or embarrassing symptoms. This can lead to people feeling isolated from their friends and family.

It can be helpful to explain to people beforehand that you are unable to eat certain foods. While you may worry about being seen as fussy, remember that many people have specific dietary requirements for all kinds of reasons. If you are unsure about what food will be at an event, you may wish to take snacks with you to guarantee you have something safe to eat.

When dining out at a restaurant, it can be helpful to check the menu beforehand so you can plan a meal that won't aggravate your symptoms. Don't be afraid to ask the waiter about what ingredients are in the dishes, or to request adjustments, for example having sauce served on the side so you can try it first.

RESEARCH FACT

A study funded by Crohn's and Colitis UK found that people with IBD often experience feelings of embarrassment, guilt, burden and disappointment around eating

If you are taking certain drugs such as steroids or immunosuppressants, you could be more vulnerable to catching infections due to having a weakened immune system. You should therefore be careful with hygiene when preparing and cooking food to help avoid gastrointestinal infections.

It is important to keep up a healthy balanced diet, so do not make any drastic changes without talking to a dietitian or consulting your IBD team. Our **Food and IBD** booklet has more information about eating healthily when you have IBD.

EXERCISE AND SPORT

Exercise has been shown to improve quality of life and have positive effects on mood, self-esteem, sleep quality and energy.

You are likely to experience times when you are less well, and are too tired, or too anxious about needing a toilet urgently, to take part in sports or exercise. While even light activity can make some people want to open their bowels, taking exercise itself will not worsen your IBD.

Adequate rest is essential, but it is also helpful to have regular physical exercise when you can, to help maintain your muscle and bone condition.

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.

Exercise may also help to improve the psychological health of people with IBD. Exercise releases endorphins, the chemicals in the brain that give you a sense of happiness and act as natural painkillers.

Some research has shown that moderate cardio and resistance exercise may help with reducing disease activity and symptoms such as constipation, although more research needs to be done to be conclusive. Research funded by Crohn's & Colitis UK found that high-intensity interval training (HIIT) could benefit people with Crohn's Disease.

If you are not used to regular exercise and find the idea daunting, it could help to include some mild 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 instead of the lift. Just getting out of the house into the fresh air can help you feel more positive. The NHS website has many free resources about exercise, particularly if you are not sure how to start. See **www.nhs.uk** for more information.

Try to incorporate exercise into your day

To help build up your confidence, plan your route in advance if you are worried about needing a toilet urgently. If you want to follow a structured exercise programme, take advice from your doctor and ask an exercise instructor to plan a programme tailored to your needs. You could also think about exercising at a gym, sports club or other indoor centre with toilet facilities.

If you want to keep up an activity but are unsure about whether it is advisable for you to carry on, ask your IBD team for an opinion, and then rely on how well you feel at the time.

For information on coping with fatigue, see our information sheet **Fatigue and IBD.**

SEX AND RELATIONSHIPS

Sex and relationships can often be affected by IBD. For example, you may be worried about feeling dirty, causing unpleasant smells or having ‘accidents’ in bed. You may feel very sore, or simply too tired for sex. Your partner may have their own worries and be anxious about whether they are hurting you.

Some people may worry about how they look, especially if they have scars from surgery. Treatments for IBD, for example enemas that are prescribed to be used last thing at night, can also affect sex life and disrupt being spontaneous.

If you can, explain the situation. Although talking openly about your condition and your concerns may be embarrassing at first, it can help to avoid misunderstandings.

You may also find that your partner is able to support you better when they know more about how you are feeling. It is also important to be aware of their feelings too.

Remember that you can discuss any worries with your doctor or nurse, if you feel they are sympathetic. Some people find that counselling helps. Our leaflet **Sexual Relationships and IBD** may be useful.

Women with IBD taking oral contraceptives can be at increased risk of developing blood clots. Severe diarrhoea can also impact your body’s ability to absorb medications, which may make the oral contraceptive pill less effective. Speak to your GP or IBD team if you have any concerns about birth control, and how that might be affected by your IBD or medication.

You should talk to your doctor if you are trying to have a baby. IBD and some of the treatments for it can sometimes have an effect on fertility. Some of the drugs used for IBD should not be taken by either partner when trying to conceive a baby or by women while pregnant. Your IBD team will advise you if you need to change your treatment. For more information, see our **Reproductive Health and IBD** and **Pregnancy and IBD** information sheets.

COPING WITH URGENCY

Many people with IBD worry about needing to use the toilet urgently when they are away from home. Pubs and chemists are often good places to go for emergency loos. If you are a member of Crohn's & Colitis UK you will receive a 'Can't Wait' card to help when asking to use toilet facilities. You can also get a radar key from Disability Rights UK to unlock some toilets for disabled people. See **Other useful organisations** at the end of this booklet for contact details.

If you are concerned about having an 'accident', you may find it helpful to carry an emergency kit containing a spare pair of underwear, moist wipes, nappy disposal bags to carry soiled pants home, a couple of clothes pegs to keep clothes out of the way, a small mirror to check you are clean, and a neutralising aerosol to disguise any odour. Using a pad for underwear may give you extra security as well. For more suggestions, see our information sheets **Diarrhoea and Constipation** and **Managing Bowel Incontinence in IBD**.

Many people find that the most active time for their IBD 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 have breakfast earlier before leaving home, while others find it best to wait to get to work before they eat.

URGENT CAN'T WAIT

PLEASE HELP – **The holder of this card has Inflammatory Bowel Disease and needs to use your toilet facilities urgently.**

Thank you.

CROHN'S & COLITIS UK

Registered charity numbers
1117148 (England and Wales)
SC038632 (Scotland)

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.

If you are going abroad, check whether your travel insurance covers existing illness provided you have your doctor’s agreement to travel. Our information sheet **Insurance and IBD** includes a list of insurance companies suggested by members. Some airlines allow you to book your seat in advance - otherwise, try to check in early for your flights to get a favourable seat. 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. Some train companies allow you to choose aisle seats, or seats close to the toilet, when booking in advance too.

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 it can be helpful to complete this cycle before you need to leave.

Before you go abroad, try to learn the words for “Where is the toilet?” in the language of the country you are visiting. We have ‘Can’t Wait’ cards in a number of languages to make it easier for you to access toilet facilities. Differences in diet can often cause quite healthy people to develop ‘traveller’s diarrhoea’, so people in resorts are usually accustomed to tourists asking for the toilets. Our information sheet **Travel and IBD** has other useful tips and suggestions.

FINANCES AND IBD

Having IBD can sometimes lead to extra expenses such as higher heating and water bills, laundry costs, taxi fares and lost days at work. Some people may be able to claim financial assistance from the government to help meet the extra costs associated with living with a long-term condition. For more information on how to apply, see our benefits guides **Claiming Personal Independence Payments (PIP) and Claiming DLA - Children under 16**.

If you live in England and have to pay for a lot of prescriptions, it may be cheaper to buy an NHS prescription prepayment certificate (PPC). This allows you to pay a fixed amount for a 3 or 12 month period, no matter how many prescriptions you need. Visit www.gov.uk/get-a-ppc for information on how to apply.

If you are in receipt of certain benefits and have a water meter, you may be entitled to a cap on your water bill through schemes such as WaterSure. Contact your water authority for more details.

People going to university or college may be able to apply for Disabled Students' Allowance (DSA). This can help meet the extra expenses that come with IBD, for example, the cost of en suite accommodation. To find out more, see our information sheet **Students with IBD: A guide for students**.

Crohn's & Colitis UK offer Educational and Vocational grants for those aged 15 or over to go toward the costs of education or training. See **www.crohnsandcolitis.org.uk/grants** for more details.

> “Disabled Students' Allowance has meant that our daughter has been able to live in en suite accommodation at university, rather than halls of residence with shared bathroom facilities. It has made a big difference.”
>
> **Andrew,** father to **Emma,** age 19, diagnosed with IBD Unclassified in 2005

FINDING A LOCAL COMMUNITY

Local Networks

Crohn's & Colitis UK supports Local Networks of volunteers across the UK. Local Networks organise events and provide opportunities to get to know other people in an informal setting, as well as to get involved with educational, awareness-raising and fundraising activities. All events are open to members of Crohn's and Colitis UK. Details on how to become a member are given at the end of this booklet.

> **Just being with other people and realising that you are not alone – and that they too have the same condition – can be reassuring.**

You may feel comforted by going to a network event, without wanting to take a particularly active role as a volunteer. Or you might want to lend a hand by getting involved in raising awareness of IBD in your local area. Families and relatives may also find it useful to meet other people with IBD.

Crohn's & 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**.

Patient Panels

You may also be able to meet others with IBD through an IBD Patient Panel. IBD Patient Panels, which are supported by Crohn's & Colitis UK, are groups of people with Inflammatory Bowel Disease who use their perspectives as patients to work with their IBD healthcare team to help improve hospital services. Visit the Crohn's and Colitis UK website for further information or email **patientinv@crohnsandcolitis.org.uk**.

MANAGING YOUR CONDITION

Managing your IBD in the ways suggested here may help you feel you can cope better with your condition. There will probably still be days when you feel down and that life is unfair, and 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 challenges of IBD. You should find that the more you look after yourself, the more you will enjoy life.

> "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

It is a bit like being on a rollercoaster, sometimes being well, sometimes being poorly, but you can live your life to the full.

Claire, age 43,
diagnosed with Crohn's Disease in 2005

Having IBD is a long journey but every journey tells a different story. Try not to let whatever is happening get you down, but do ask for help and avoid becoming isolated. There is plenty of help and support out there.

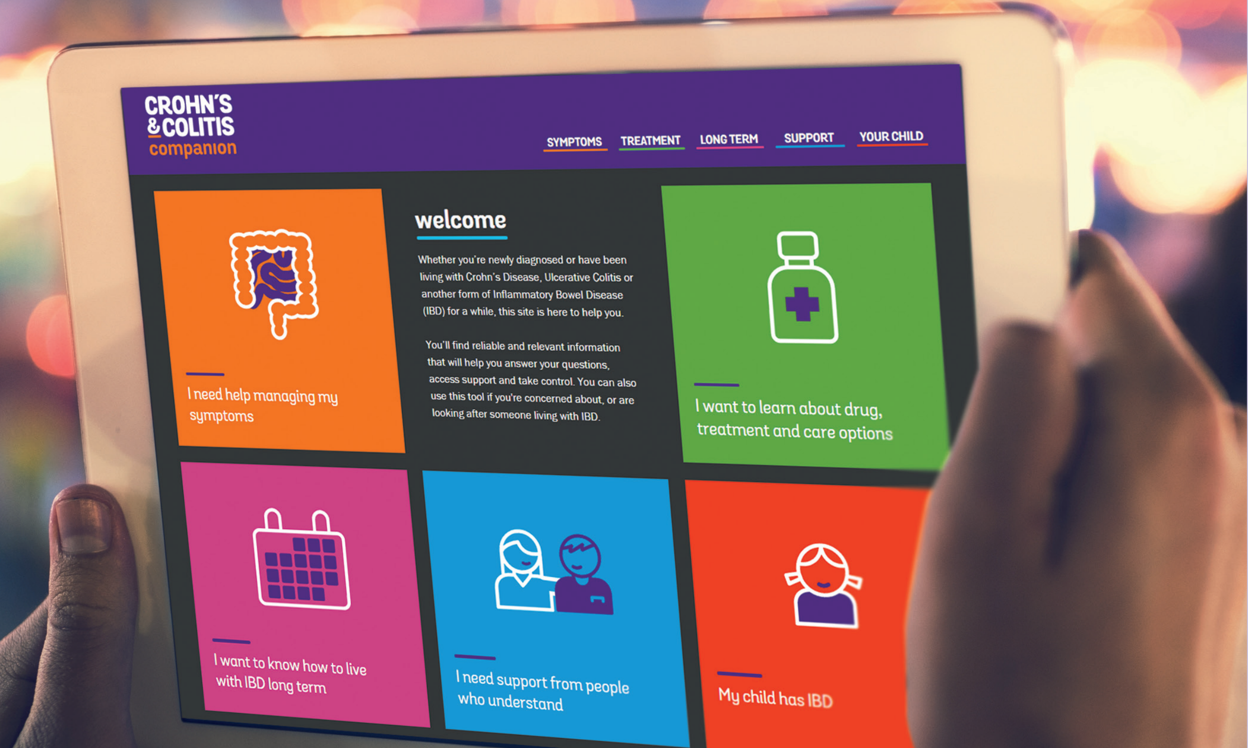
Aisha, age 45,
diagnosed with Ulcerative Colitis in 1990

I'm not going to let UC take over my life, although it's had a good go! We're a special kind of person to deal with everything IBD throws at us. There are good days through the bad. We just have to keep going.

Sharon, age 37,
diagnosed with Ulcerative Colitis in 2005

Our publications are the most reliable source of information on Crohn's and Colitis.

Visit crohnsandcolitis.org.uk/publications or for our online companion resource visit companion.crohnsandcolitis.org.uk



welcome

Whether you're newly diagnosed or have been living with Crohn's Disease, Ulcerative Colitis or another form of Inflammatory Bowel Disease (IBD) for a while, this site is here to help you.

You'll find reliable and relevant information that will help you answer your questions, access support and take control. You can also use this tool if you're concerned about, or are looking after someone living with IBD.

CROHN'S &
COLITIS UK

HOW WE CAN HELP YOU

We're here for you whenever you need us. Our award-winning publications on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment. Whatever you need, we'll help you find answers, access support and take control.

All publications are available to download from **www.crohnsandcolitis.org.uk/publications.** Health professionals can order booklets in bulk by using our online ordering system.

If you would like a printed copy of a booklet or information sheet, please contact our helpline - a confidential service providing information and support to anyone affected by IBD.

Our team can:

- help you understand more about Crohn's and Colitis, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of Crohn's or Colitis

Contact us by telephone on **0300 222 5700** or email **helpline@crohnsandcolitis.org.uk**

See our website for LiveChat
www.crohnsandcolitis.org.uk/livechat

OTHER USEFUL ORGANISATIONS

Bladder and Bowel Community
www.bladderandbowel.org

Colostomy Association
www.colostomyassociation.org.uk

Crohn's in Childhood Research Association
www.cicra.org

Disability Rights UK
www.disabilityrightsuk.org

IA – The Ileostomy and Internal Pouch Support Group
www.iasupport.org

The British Dietetic Association
www.bda.uk.com

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PAYMENT DETAILS

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

Individual membership

○ £15 per year Direct Debit

○ £19 Cheque/Credit or Debit Card per year

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 & 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 8 3 0 1 9 6

OFFICIAL USE ONLY

OUR REFERENCE

Instructions to your Bank or Building
Please pay Crohn's & 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 Crohn's 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 confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand that the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

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 like to receive this information.

Please return this form along with payment to Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE