Living with IBD

Improving life for people affected by inflammatory bowel diseases

www.crohnsandcolitis.org.uk

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About this booklet
If you have recently been diagnosed with Crohn’s Disease or Ulcerative Colitis, (the two most common forms of Inflammatory Bowel Disease – IBD), you are likely to have many questions about how to manage your condition day-to-day. You may still have questions even if you have had IBD for some time. This booklet looks at some of the situations you may face, and contains ideas and suggestions based on the advice of professionals and the experiences of other people with IBD.

All our publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. However, they are prepared as general information on a subject, and are not intended to replace specific advice from your own doctor or any other professional. Crohn’s and Colitis UK does not endorse or recommend any products mentioned.

About Crohn’s and Colitis UK
We are a UK-wide charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 30,000 members and 70 Local Groups throughout the UK.

Membership costs £15 a year but free membership is available for 16-18 year olds, students, and people over 65. People on lower incomes may join at a reduced rate.

We do not charge for copies of this booklet, but we do need funds to be able to produce it. Please consider making a donation or becoming a member of Crohn’s and Colitis UK. To find out how call 01727 734465 or visit www.crohnsandcolitis.org.uk
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Living with Inflammatory Bowel Disease (IBD)

The two main forms of Inflammatory Bowel Disease (IBD) are Ulcerative Colitis (UC) and Crohn’s Disease. Living with one of these conditions can be quite a challenge.

In both Crohn’s and UC, parts of the digestive system, usually the intestines (also known as the bowels), become swollen, inflamed and sore.

Common symptoms can include pain, diarrhoea (sometimes with blood), weight loss and tiredness. Some people develop anaemia or have problems with their joints, skin and eyes.

Both Crohn’s and UC are chronic (long term) conditions that can flare-up unpredictably, although you may also have periods of good health (remission). There is no cure at present.
How you may feel at first

After feeling unwell for quite a while, most people’s reaction to diagnosis is a mixture of shock, anxiety, uncertainty – and sometimes, relief. Shock because you have been told that you have an ongoing disease – something that you’re stuck with – and anxiety at the thought of taking daily medication for a long time, perhaps indefinitely.

You may also feel uncertain and unsure what to expect. After all, you may not have heard of IBD, Ulcerative Colitis, or Crohn’s Disease before. So it’s natural to feel concerned and confused, particularly when doctors don’t yet know the actual cause of the illness.

But you may also be relieved to find that your symptoms have an identifiable name, and that your illness can usually be controlled with medication, although surgery may sometimes be necessary.

It may also help to know you are not alone. Over 260,000 people in the UK have IBD, and work is continuing to find better treatments and, eventually, a cure.
Your feelings later on

In the longer term, it is often the ongoing and unpredictable nature of the disease that can be especially difficult to live 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. You may find that, if your medication is not working as well as had been hoped, your doctors recommend surgery.

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

How you see yourself

It is common to feel angry and upset about being diagnosed with a disease like IBD and some people initially respond by being in denial. While no-one can pretend it is easy coming to terms with an illness, accepting you have a medical condition, and that there may be times when you have to take things more easily, can help you keep a balance in your life.

It may mean, for example, that when you have a flare-up you have to make adjustments and take time to recuperate. On the other hand, when you are well you may be able to live life to the full. Many people with IBD do well in their studies and are able to work and have successful careers.
Some people also find that they feel more in control if they learn all they can about their condition and how to manage it. There are now many good sources of information, some of which are mentioned in this booklet. But of course, everyone is different and how much detailed information you wish to have will be entirely up to you.

How other people see you

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

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 put your symptoms aside as trivial.
You may find 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 these diseases. This situation is not helped because it is commonly accepted that anxiety and stress can have an adverse effect 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 may 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.

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

You may find that if you can 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 also help you to feel more in control of the situation and less anxious about your symptoms and treatment.

It could be 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 fear rather than lack of sympathy.

IBD is an embarrassing illness and on the whole we tend not to discuss bottoms, bodily waste, toilets and bowels with each other, even people we’re close to. Sheer shyness may prevent you from being able to explain as much as you’d like to another person.

If you feel embarrassed about explaining your IBD, you could invite your family and friends to read about it. At Crohn’s and Colitis UK we publish a range of booklets and leaflets about IBD, which could give your friends and relations a chance to understand the disease better. Our website also has a lot of helpful information about IBD.

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

With some people you may not want to go into detail. You could just say something like: “I have a gut condition which means I have to rush to the toilet very suddenly” or “I have an illness which 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.

What to say at work

Some people worry that it might be a risk telling their employers about their Crohn’s or UC. It is often better to do so. If you are concerned, you may find it useful to read our information sheet Employment and IBD: a guide for employees. We also have a guide for employers with information about IBD and what they can do to support you.

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 have to take your tablets discreetly out of sight or keep making excuses about tummy upsets. Explaining that it is not infectious is always worthwhile – people often worry about this but don’t like to ask.

On a more practical level, make sure you know all about your firm’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). You can find more information on this and other benefits, together with details of helpful organisations, on our website or by ringing our Information Line (contact details are given at the end of this booklet).

“I found out what my rights are at work, and it made me feel more confident when I talked to my manager about what changes could help me manage my IBD better, day to day.” David
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 specialist team. It can be really 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.

Some words you might find useful when talking to the doctor or nurse are ‘motion’, ‘stool’ or ‘bowel movement’. But they will have heard every word in the book, so use what you feel comfortable with. If they ask you to describe your stools, you could describe them as ‘like toothpaste’, ‘like a cowpat’, ‘like sheep’s droppings’. Other words and phrases you might find useful are ‘urgency’, ‘having an accident’, ‘fear of not getting to the loo in time’, ‘explosive diarrhoea’, ‘gas’, ‘flatulence’ or ‘wind’.

These are just suggestions – if you think out your own descriptions in advance it can save possible embarrassment in the surgery.
Your doctor 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.

It can also be helpful to:

- Make a list of the important questions you want to ask, and 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 using your list.
- Take a friend or family member with you as they can remind you of what was said.

You may also find it helpful to look at some of our other information sheets and booklets, such as **Drugs used in IBD**, which gives more information about the different medications available to treat Crohn’s and Ulcerative Colitis. We also produce two leaflets on surgery for IBD.

“When I was first diagnosed, I was warned not to just look on the internet – they said to go to the ‘Crohn’s and Colitis UK’ website as their information is reliable.” Hannah
Alternative and complementary medicines

When there is no obvious cause or cure for an illness it’s natural to think about other approaches.

There are a whole variety of these medicines available – homeopathy, acupuncture, aromatherapy, hypnotherapy, herbal remedies, special diets, relaxation techniques – to name but a few. Some are presented as alternatives to orthodox treatment; others say they are ‘complementary’, which means they may help you in addition to the treatment you are already receiving.

Although there is no hard evidence that any of these actually work, many people have felt they have benefited. For instance, while relaxation exercises may only sometimes alleviate symptoms, they may help someone cope better with the everyday stresses of living with a long-term condition like IBD.

However, 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 remedies (including ‘herbal’ remedies), go on an extreme diet, or have procedures like colonic irrigation, without talking to your consultant.
“Sometimes it is frustrating living with UC, but other times I am very proud of what I have been able to achieve even with the disease.” Daisy

Taking care of yourself

Major life changes can cause anxiety and stress. Getting used to the idea that you have a long-term and potentially embarrassing illness like IBD is going to take time, and feelings of anxiety and depression are understandable. As well as having to deal with the physical symptoms like pain, diarrhoea, and fatigue, you also have to deal with your emotional reactions.

So, if you do feel worried, or depressed, don’t dismiss your feelings as irrational or signs of weakness. Try not to feel guilty or that you’re making a fuss about nothing if you need to have a rest or to take time off work.

Remember that you suffer from an ongoing illness and there are bound to be times when you are going to feel stressed and tired. When this happens it really is important that you take care of yourself and take as much rest as you need.

Just because you can’t perhaps do all the things you might like to, does not mean you’re not coping. It probably means you’re doing very well in what is a difficult situation. You may find our information sheet Staying well with IBD helpful.
Diet and IBD

Research is continuing into links between diet and IBD. So far there is no clear evidence that any particular food or food additive directly causes Crohn’s or UC. However, some people have found that certain foods do seem to make their symptoms worse, and that cutting out these foods reduces the chance of a flare-up.

As everyone is different, it may be worth keeping a food diary to see if you can work out whether there are food triggers that set off your IBD. But do remember how important it is to keep up a healthy balanced diet, and don’t make any drastic changes without talking to a dietitian or consulting your doctor.

You may also be advised to avoid eating certain ‘hard to digest foods’ if you have Crohn’s and tend to get strictures (narrow sections of the intestine).

Our Food and IBD booklet gives more information about eating healthily when you have IBD.
**Exercise and sports**

Having IBD doesn’t always mean you have to give up leisure and sporting activities, although there are some people for whom fatigue is a major problem.

And, for many people with IBD, there are likely to be times when they are less well, and feel too tired or too anxious about needing a toilet urgently, to take part in sports or exercise.

However, there are people with IBD who manage to keep up a favourite sport, sometimes even to professional level. If you want to keep up an activity, but are worried about whether it is safe for you to carry on, ask your doctor for an opinion, and then rely on how well you feel at the time.

It is actually helpful to take some sort of regular physical exercise if you can, since this can help maintain your muscle and bone condition. One good way is to try and include some activity into your daily lifestyle. It may simply be walking to the shops if you can, rather than taking the car, or using the stairs at work instead of the lift.

If you decide you want to follow a structured exercise programme, then take advice from your doctor and use an exercise instructor to plan a programme tailored to your needs.

For more 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 in the area anyway, or simply too tired and exhausted for sex. Your partner may have their own worries and be anxious about whether they are hurting you.

Some people may worry about how they look, especially if they have surgery scars. Treatments for IBD can also affect a sex-life. For example, enemas are often prescribed to be used last thing at night, and this can be disruptive to 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.

Remember that you can discuss any worries with your doctor or nurse, if you feel they are sympathetic. Some people find counselling helps – see the Counselling section in this booklet. Our leaflet, Sexual Relationships and IBD may also be useful.

IBD, particularly Crohn’s Disease, may reduce the reliability of the oral contraceptive pill. If this is of concern, you may wish to think about alternative methods of birth control.
It is also a good idea to talk to your doctor if you’re trying to start a family. IBD and some of the treatments for it can sometimes have an effect on fertility. Also, 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 doctor will be able to advise you if you do need to change your treatment. You may also find it helpful to read our information sheets on Fertility and IBD and Pregnancy and IBD.

Finding support

If you join Crohn’s and Colitis UK you will have the opportunity to go to local Group meetings. Groups can often provide a lot of support along with the chance to get involved with activities such as running information stands and fundraising for research.

You may find that just being with other people and realising that you are not alone, that they too have the same condition, can be reassuring.

You may feel comforted just by being in the group, without feeling that you have to take a particularly active role. Or you may want to speak up about how you cope with your condition, and share your ideas with others. Either way, many people with IBD feel that they benefit from such group meetings. Relatives may also find it useful to meet other people with IBD.

You may also be able to meet others with IBD through a hospital patient panel or group. Your hospital IBD team will know if there are groups like this in your area.
People sometimes feel the need to speak to someone neutral who isn’t a nurse, doctor, relative or friend, but who understands IBD. We have a telephone-based confidential supportive listening service, Crohn’s and Colitis Support, staffed by trained volunteers all of whom have experience of living with IBD.

Counselling

Talking to a counsellor may also help you and your family to understand and to adjust to the challenges of living with IBD.

You may find that there is a counsellor available through your GP’s practice, or you can ask the IBD team or social worker at the hospital you attend. Our information sheet Counselling and IBD has more information on how to find a counsellor.

“The way my counsellor put my experiences into other words really helped me to understand how I was feeling, and what I could do to help myself.”

Sarah
Practical tips

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

Pubs and chemists are good places to go for emergency loos. If you are a member of Crohn’s and Colitis UK, you receive a ‘Can’t Wait’ card to help when asking to use the toilet facilities in shops or offices. You can also get a key for public toilets for disabled people from the Disability Rights UK Radar Shop (see Other useful organisations).

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

When going on holiday make sure you take enough medication with you, with a little extra in case of delay. Take a note of the medication you use and carry a doctor’s letter with you.

Check whether your travel insurance will cover an existing illness provided you have your doctor’s agreement to travel. While Crohn’s and Colitis UK cannot recommend particular companies or policies, our information sheet Insurance and IBD includes a list of companies suggested by members. Some airlines allow you to book your seat in advance, otherwise try and check in early for your flights. If you are concerned about needing to visit the toilet when the seatbelt light is on, have a word with an air-steward before take-off.

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

Before you go abroad, try to learn the words for “Where is the toilet?” in the language of the country you are visiting. We have ‘Can’t Wait’ cards in a number of languages. Remember that differences in diet can often cause quite healthy people to develop ‘traveller’s diarrhoea’, so people in resorts are usually well used to tourists asking for the toilets. Our leaflet, Travel and IBD has other useful tips and suggestions.
Help and support from Crohn’s and Colitis UK

Crohn’s and Colitis UK exists to help improve the lives of all those affected by Crohn’s Disease and Ulcerative Colitis, so do join. It’s the best way to find good quality and reliable information about living with IBD. All our booklets and information sheets are available to download from our website. If you would like a printed copy, please contact our information line. We also offer a range of other support services – see below for details.

You can complete the membership application form in this booklet, contact the office for a new one or join online at www.crohnsandcolitis.org.uk.

Crohn’s and Colitis UK Information Line: 0845 130 2233
open Monday to Friday, 10am to 1pm, 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 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: 0845 130 3344
open Monday to Friday, 1pm to 3.30pm and 6.30pm to 9pm, 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.
Our Parent to Parent service provides telephone support for parents of a child with IBD. It is staffed by trained volunteers all of whom are also parents of a child with IBD. We also have a Disability Benefits Service which can give general guidance over the phone about Disability Living Allowance, Attendance Allowance and the new Personal Independence Payment. To make an appointment, contact the Information Line. For more details of these and all our other services, see our website.

**Other useful organisations**

Bladder and Bowel Foundation  
[www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)  
0845 345 0165

Colostomy Association  
[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)  
0800 328 4257

Core – Fighting Gut and Liver Disease  
[www.corecharity.org.uk](http://www.corecharity.org.uk)  
020 7486 0341

Crohn’s in Childhood Research Association  
[www.cicra.org](http://www.cicra.org)  
020 8949 6209

Disability Rights UK  
[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)  
020 7250 8181

IA – The Ileostomy and Internal Pouch Support Group  
[www.iasupport.org](http://www.iasupport.org)  
0800 0184 724
Yes! I’d like to join Crohn’s and Colitis UK as a member

You can become a member if you are 16 years or over by paying online at [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk), or complete and return this form with a cheque/p.o (please see overleaf for payment details).

If joining and 16 or over, please complete the white section below. If joining as a parent, or relative of a patient, please complete both sections below.

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Tick if
- [ ] You give permission for us to inform local groups, so they can contact you
- [ ] A patient
- [ ] A parent or relative applying for an under 16 year old (please complete the pink section below)
- [ ] A relative of a patient
- [ ] A health professional
- [ ] A relative or friend of a patient wanting to put their name on the Can’t Wait Card (please complete the pink section below)
- [ ] A friend or interested party
- [ ] Have you been a member of our Charity before?

If you are a parent/guardian/carer applying for a child, or if you are a relative/friend 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 under 16.

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- [ ] I confirm the above information may be held by the charity
- [ ] I give permission to pass the above information to the charity’s local Groups including the Family Network (see [www.crohnsandcolitis.org.uk/family-network](http://www.crohnsandcolitis.org.uk/family-network))

Signed

Date

(Patient named above, or parent/carer of child)
As a member you will receive booklets and a membership card, plus our quarterly membership mailings.

- **Individual Membership** £15 annually
- **Overseas Membership** £20 annually
- **Student Membership (in full-time higher education)** Free of charge
- **65 and over** Free of charge

Please complete the form below and return with your payment, if applicable. Additional donations are always welcome.

New UK members on lower income due to health/employment circumstances may join at a reduced rate – please contact the Membership Team on 01727 734465 for more information.

**Subscription** £

**Additional donation** £

**Total** £

☐ I enclose a cheque/postal order payable to Crohn’s and Colitis UK.

Signed ___________________________  Date ___________________________

If you do not wish to become a member you can still support us and help us to improve the lives of people with Crohn’s and Colitis by making a donation.

☐ £5  ☐ £10  ☐ £25  ☐ £50  ☐ £100  ☐ Other

Prefer to donate by card? Please go through the “donate” button on our website’s homepage.

If you’d like to make regular donations by Direct Debit or Transfer, or through Give As You Earn, please call the Membership Team.

If you’d like your donation to be acknowledged please tick one option (and ensure you have completed your name and address overleaf)

☐ I’d like an acknowledgement by post  ☐ I’d like an acknowledgment by e-mail

☐ I don’t want an acknowledgement, thanks!

Signed ___________________________  Date ___________________________

Gift Aid: 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 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.

☐ I am a UK taxpayer and wish Crohn’s and Colitis UK to reclaim tax on this donation and all future subscriptions or donations.

Signed ___________________________  Date ___________________________

Please post this completed form to:
Crohn’s and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH

In the case of query please call the Membership Team on 01727 734465

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 aim to comply with the Data Protection Act 1998.
How we write our information

Crohn’s and Colitis UK is an accredited member of the Information Standard scheme for health and social care information producers. This means that we have passed a rigorous assessment to ensure that our information is

- clear
- accurate
- balanced
- evidence-based and
- up-to-date

For more information see our website at www.crohnsandcolitis.org.uk and the Information Standard website at www.theinformationstandard.org.

How to contact us with comments or questions about this booklet

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