

Fatigue (Tiredness)

Living with a condition like Crohn's or Colitis can be tiring work. But many people with Crohn's or Colitis also live with something called fatigue. Fatigue can feel like never-ending tiredness, a lack of energy, or a feeling of exhaustion that does not go away after rest or sleep. But it can be very difficult to describe as it affects each person differently.

This information explains what fatigue is and what may cause it. It also gives tips on how to manage your fatigue, and how to talk to other people about how you feel.

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Key facts about fatigue

1. Fatigue is extreme tiredness that does not go away with the usual amount of rest or sleep.
2. Fatigue is a common feature of Crohn's and Colitis but is not often talked about.
3. Fatigue affects around 7 in 10 people when they have active inflammation from their Crohn's or Colitis (in a flare-up).
4. Fatigue affects around 4 in 10 people when their Crohn's or Colitis is not active (in remission).
5. There are many possible causes of fatigue.
6. Many people with Crohn's or Colitis say fatigue is the most difficult symptom to deal with.
7. There are many ways to help manage fatigue and limit its impacts on your life.

What is fatigue?

“I think there can be a bit of a stigma attached to fatigue where patients might struggle through it not wanting to admit to it for fear of being seen as “lazy” when in fact fatigue & tiredness are in entirely different leagues.”

Shirley

Living with Colitis

Fatigue is an unpleasant feeling of ongoing tiredness that does not go away with the usual amount of rest or sleep. For people with Crohn's or Colitis, fatigue can be:

- Physical (low energy or strength, a feeling of heaviness).
- Mental (low motivation, concentration, or alertness). A feeling of 'brain fog'.
- A combination of physical and mental.

People with other conditions such as diabetes, multiple sclerosis, and cancer also experience fatigue. It's a real symptom and can be very hard to live with.

One of the hardest things about fatigue is that it can be unpredictable. You may notice your energy levels change from day to day, or even hour to hour. Some people say for them it's like 'hitting a brick wall.'

But fatigue can also build up very slowly, so slowly that you do not notice it. This can make it hard to tell what's normal for you.

As an invisible symptom, it is sometimes a hard thing to explain to others. But it's important to remember that fatigue is not a personal failing and is nothing to be embarrassed about.

“I'll be functioning in what I consider to be a perfectly normal way and feeling great one minute, and the next minute, for no reason whatsoever, I'll suddenly drain and have no energy.”

Fatigue in IBD study participant

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How many people have fatigue?

If you have fatigue, you're not alone. Around 7 in 10 people with Crohn's and Colitis have fatigue during a flare-up. Fatigue is also common when Crohn's and Colitis is not active (in remission). Around 4 in 10 people have fatigue when their Crohn's or Colitis is in remission.

Fatigue seems to be more common, or more severe in certain groups. These include:

- People who have previously had surgery
- Women
- People who are experiencing depression or anxiety
- People who are experiencing complications outside the gut, like joint or eye problems
- People living with Crohn's

There has been less research into fatigue and Microscopic Colitis, or fatigue and Inflammatory Bowel Disease Unclassified. However, studies so far suggest fatigue is a common symptom in both of these conditions as well.

“Fatigue is arguably the most difficult intangible part of IBD. The invisible battle that the body is fighting with IBD and medications is deeply frustrating. This can overwhelm plans, exercise regimes, working output and is incredibly difficult to articulate to others.”

Kathleen

Living with Crohn’s

Ways you might notice fatigue affecting your life

Sometimes it may be hard to work out whether your tiredness is normal for you or not. It may even be someone else that spots you have fatigue.

Fatigue might not affect every part of your life - you may find that you can still do some things, but other things are harder. One way of trying to work out if you have fatigue is to look at the different parts of your daily life and see if things are harder than you would expect them to be.

“When I feel fatigued my whole body and brain shutdown, like something has zapped every particle of energy from my body and mind. I cannot think, I cannot focus, I have no energy to do anything.... simple everyday tasks such as getting up, putting on my slippers or making a cuppa feel like a huge challenge, like climbing a mountain with boulders strapped to my back”

Donna

Living with Crohn’s

Physical activity

If you have fatigue, you may find physical activity harder than you would expect. This could mean things like sport, but also everyday activities like household chores, or going food shopping . On bad days, even walking to the bathroom may feel like a marathon. Maybe you feel fine doing exercise but notice it takes you much longer to recover afterwards.

Social activities

Living with fatigue can make seeing friends and family difficult for some people. You may find yourself cancelling plans or avoiding meeting up with people. You may notice that concentrating and engaging in conversations is more difficult. You may start to notice you stop doing things like going on holiday, seeing friends, or taking part in hobbies. Or you may push yourself to do things but feel unwell afterwards. Other people may notice you seem withdrawn and not your usual self.

Emotions

Anything that affects your life as much as fatigue can change your mood. If you cannot do as much as you would like, you may feel frustrated and angry. Some people find fatigue makes them feel isolated and lonely. You may feel that you have lost some control over your life. For some people, their fatigue may be associated with anxiety or depression.

Relationships

You may notice fatigue impacting your relationships with people close to you. You may feel that people do not understand how tired you are. Or you may start to feel guilty that your loved ones are doing extra things to help. Fatigue can also affect intimate relationships and your sex life.

Memory and concentration

You may notice fatigue makes it difficult to think clearly. Fatigue can affect some people's concentration and memory. With severe fatigue, some people feel so tired they cannot speak properly and stumble over their words. Some people call this 'brain fog.' This can make things like work challenging.

“I’ve sat in the kitchen and cried, because I can’t make a decision on something and the children are asking. And I’m so tired.”

Fatigue in IBD study participant

Work and education

You may notice that fatigue is impacting your work. You may feel like you’re not keeping up with others like you usually would. Fatigue is reported as one of the main reasons people with Crohn’s and Colitis have trouble at work. This may mean cutting down hours or leaving work altogether. Our information on [employment](#) has further guidance and tips on how to manage this,

For students, fatigue can make keeping up with work and exams hard. It may also affect things like socialising, volunteering, and sports.

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Talking to others about fatigue

A bit like pain, fatigue can be hard to explain to other people. Here we give you some tips on how to describe fatigue to other people. It may also help to check out [It Takes Guts](#) for more help on talking about fatigue and other parts of your condition.

“I don't feel like this very often but I do wish that when I do feel fatigued that others could understand that I'm not 'just tired', I'm totally exhausted, physically and mentally. I think there needs to be a lot more understanding surrounding fatigue.”

Donna

Living with Crohn’s

Finding the words

People feel fatigue in different ways. Try to write down some words that get across how you feel. Or you may find it helpful to write down how it's affecting your life.

- Have you stopped seeing friends?
- Are you working at weekends to try and catch up on work?
- Are you not eating as much because you're too tired to cook?
- Are you forgetting important things?
- Have you stopped being intimate with a partner?
- Are you missing deadlines at work or college?

In one of our studies, people with Crohn's and Colitis used some of the following phrases to describe their fatigue:

"Brain fog"

"A big black hole"

"Completely wiped out"

"Just shattered"

"Zombie mode"

"Just feeling very, very weary, and no inner energy...I'm "bone weary"



Letting your healthcare team know

A lot of people with Crohn's and Colitis live with fatigue, but it's rarely asked about in clinics.

You may find it harder to talk about fatigue if your healthcare team do not ask you about it. But it's important that you feel able to talk about your concerns.

The 2019 IBD UK Survey showed:

- Nearly 5 in 10 people are not asked about fatigue in their appointments.
- But 4 in 10 say fatigue is their biggest worry.
- When doctors ask about fatigue, patients are more likely to:
 - Rate the quality of their care highly.
 - Report feeling more able to cope.

Telling doctors and nurses you are tired may not always ring the same alarm bells as other symptoms of your Crohn's or Colitis. But living with ongoing fatigue that stops you living your normal life is a valid concern. So, you may have to push more than usual to make sure you get your fatigue assessed.

It may help to prepare questions before you have your clinic appointment. Our appointments journal can help you with this. It may also help to have a think about words that describe how you are feeling. It can also help you communicate how fatigue and other symptoms are impacting you.

“By far the most difficult symptom to endure. It saps you physically and mentally. It's incredibly hard to explain and understand - even for those who suffer it.”

Anonymous

Living with Crohn's

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Measuring fatigue

Crohn's & Colitis UK helped to create a fatigue scale for people with IBD. You can use this to assess how severe your fatigue is and the impact it has on your daily life. You can find the scale at www.crohnsandcolitis.org.uk/fatigue-scale.

If you find it difficult to talk about fatigue, you may find it helpful to use the results to discuss your fatigue symptoms with your healthcare team.

The causes of fatigue

There are lots of ways in which Crohn's and Colitis may cause fatigue. And you may find there are a mix of things making you feel fatigued.

Inflammation and disease activity

We know that fatigue is more common in people when they have active inflammation in the gut. This may seem obvious - that when you're most unwell, you feel more tired. But it's not just the symptoms like pain and diarrhoea that can lead to fatigue, but also the chemicals released from inflammation. The chemicals released into your blood when you are ill can affect your brain and muscles, making you feel weak, sleepy, less hungry, and less motivated.

Diet and nutrients

You may find that your Crohn's or Colitis makes it hard to get enough nutrients into your body. This may contribute to you feeling fatigued. If your gut is inflamed and sore it cannot soak up (absorb) the nutrients your body needs. Poor nutrition, also called malnutrition, may also be caused by diarrhoea, or not eating as much. If you have had surgery to remove part of your gut this can make it harder for your body to absorb nutrients as well.

If you have low levels of a nutrient or vitamin this is called a deficiency. Fatigue may be linked with low levels of:

- Iron
- Vitamin B12
- Vitamin D
- Folate
- Thiamine
- Calcium
- Magnesium
- Selenium

Iron deficiency is one of the most common deficiencies in Crohn's and Colitis and can lead to iron deficiency anaemia.

Anaemia

Anaemia is when you have low levels of healthy red blood cells in your body. Red blood cells carry oxygen around your body. And oxygen is one of the key ingredients that gives our body energy. So, if you have anaemia, your body cannot get enough energy, and you can become tired.

Anaemia can make people feel breathless or dizzy. It can also give you headaches. Anaemia is measured using haemoglobin levels.

If you think you may have symptoms of anaemia, speak to your GP or IBD team.

Anaemia can be a complication of Crohn's and Colitis. Around 2 in 10 people with Crohn's or Colitis have anaemia. It's more common in people who are admitted to hospital with active disease. Around 7 in 10 patients admitted to hospital with active Crohn's or Colitis have anaemia.

There are many different types of anaemia. In Crohn's and Colitis, the most common type of anaemia is iron deficiency anaemia. Iron is vital for making red blood cells. In people with Crohn's and Colitis, iron deficiency anaemia can happen because of:

- Poor absorption of iron in the gut
- Inflammation using up iron
- Bleeding
- Not eating enough food with iron in it

Other types of anaemia seen in people with Crohn's and Colitis are:

- Anaemia of chronic disease
- Vitamin B12 deficiency related anaemia
- Folate deficiency related anaemia

Mental health

Anxiety, depression and stress have all been associated with fatigue in people with Crohn's and Colitis. Often, they are seen together, so it's hard to know if anxiety, depression and stress are causes of fatigue, or the result of fatigue. Stress can trigger inflammation, pain and difficulty sleeping. These symptoms may also add to fatigue.

Other complications or conditions

People with non-gut (extra-intestinal) complications of Crohn's and Colitis, like joint or eye pain, seem to have higher levels of fatigue. People who have had surgery for their Crohn's or Colitis also seem to have higher levels of fatigue.

We know that around 3 in 10 people who have Crohn's or Colitis carry on having symptoms like diarrhoea or constipation even when in remission. For some people, these symptoms are due to living with Irritable Bowel Syndrome (IBS) as well as Crohn's or Colitis. Fatigue has also been associated with IBS.

It's worth thinking about whether your fatigue could be due to another condition. Having Crohn's or Colitis gives you a slightly higher risk of having another immune-mediated conditions like rheumatoid arthritis or ankylosing spondylitis. People with these conditions also experience high levels of fatigue.

Thyroid disorders, diabetes and kidney disease can all cause fatigue in the general population.

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis or ME, is a long-term illness with many symptoms. The most common symptoms are extreme tiredness and generally feeling unwell. CFS may be diagnosed if you suffer from long-term fatigue that cannot be explained by other causes. There is growing evidence that inflammation in the gut may contribute to the development of CFS.

Medicines

Steroids and drugs that affect the immune system, including azathioprine, mercaptopurine and methotrexate, have been linked to fatigue in some people. Steroids

can affect sleeping patterns which may contribute to fatigue. Long-term use of steroids has been associated with muscle and bone weakness.

Poor sleep

Many people with Crohn's and Colitis experience sleep problems, even during remission. One study found almost 5 in 10 people report poor sleep during remission, and almost 8 in 10 people with active disease. Factors that may lead to poor sleep include:

- Pain and discomfort
- Going to the toilet during the night
- Feeling and being sick
- Side effects of medicines
- Depression, anxiety, and stress
- Worries about your stoma leaking

Bacteria in the gut

Early research suggests that the bugs that live in your gut (the gut microbiome) may be linked with fatigue.

Research has shown that people with Crohn's and Colitis who have fatigue seem to have a less diverse gut microbiome than people with Crohn's and Colitis who do not have fatigue. But although they may be linked, we do not know whether one causes the other. What we do know is that there is a direct link between the gut and brain. This is called the gut-brain axis. Abnormal levels of gut bacteria have also been seen in other conditions that have fatigue as a main symptom, like chronic fatigue syndrome and depression.

Muscle mass and strength

People with Crohn's and Colitis seem to have smaller muscles and lower muscle strength than people without Crohn's or Colitis. This is likely due to many factors like levels of nutrition, and not using muscles as much during illness. The chemicals released during a flare-up may also affect muscle mass and strength.

Ways to manage your fatigue

Fatigue may be caused by many different things. This means there are many different things you and your healthcare team can try to help take control of your fatigue.

Check if you are having a flare-up

If you are experiencing fatigue this could be a sign of a flare-up. So, it's worth letting your IBD team or GP know early on. Getting your condition under control is one of the most important things you can do to help fatigue. By controlling inflammation and symptoms such as pain, you may be able to reduce your fatigue.

If you speak to your healthcare professional, they may ask you to do some tests. You may be asked to get your blood and poo checked. You may be sent for a camera test or scan to check if your gut shows any signs of active disease. Our information on [tests and investigations](#) explains some of these tests in further detail.

Check if you have anaemia or nutrient deficiencies

If your disease is under control, the next step may be to check your bloods for anaemia or low levels of nutrients. However, not all nutrients can be tested easily. Your doctor may check your iron, vitamin B12, folate, vitamin D, magnesium and calcium levels.

Try to ask your healthcare team what they are testing for. It may be helpful to keep a note of your results so you can compare them in the future. Even if all your bloods are ok, it may help to feel involved in your care and to know the numbers. You can use our [appointments journal](#) to help with this.

If you have iron deficiency anaemia then you may be given a top up either with tablets or through a drip, which often helps fatigue. However, people who do not have anaemia but do have low iron stores usually do not get benefit in fatigue levels after having iron replacement. Vitamin B12 and folate are also used to treat some types of anaemia. In more severe cases, a blood transfusion may be needed to treat your anaemia.

Topping up your vitamin D may help your fatigue, but there is not much evidence for this (but it is good for your **bones**, so it's worth treating if you do have low levels.) There is some evidence suggesting that high dose thiamine may help reduce fatigue in people with Crohn's and Colitis. But more research is needed before this can become a routine treatment.

Managing other symptoms

If you're experiencing other symptoms that affect your energy levels, like bloating or pain, you might want to look at our information on **managing symptoms**. Some people find it helpful to keep a diary of their symptoms. It may also help to note down what else is going on in your life, such as work stress or diet changes to see if there are patterns. This may help you to make changes to your day-to-day life, and track whether it helps your symptoms.

Diet and hydration

There's no single diet that's been proven to help fatigue in people with Crohn's or Colitis. But eating a varied and healthy diet may help. Many people with Crohn's or Colitis do not get enough nutrients in their body for various reasons. It may be especially hard in a flare-up, or if you notice certain foods worsen your symptoms.

If you're unsure of what to change in your diet, it may be helpful to see a dietitian. You can speak to your GP or IBD team about a referral. We also have information on **food**.

You may find certain foods trigger, worsen, or help your symptoms. However, if you change your diet and cut out certain foods, this may lead to some nutrient deficiencies. Try to speak to a dietitian or other healthcare professional for advice before cutting out foods.

Some people find taking other supplements, such as omega-3 oils (found naturally in oily fish and some other foods) helps with their fatigue. However, there is little scientific evidence to support this. Some vitamin supplements can affect how oral medicines are absorbed, so try to let your healthcare team know if you are taking any, and they can advise on how to space the tablets out during the day.

It can be easy to become dehydrated, especially when you're in a flare-up. You may find drinking little and often may be easier than drinking lots in one go. If you're being sick a lot or having lots of diarrhoea, you may also need to replace sugars and salts. Over-the-

counter rehydration solutions may help. But if you're very dehydrated you may want to speak to your IBD team for advice. Our information on [dehydration](#) gives more details around this topic.

Physical activity

It may sound odd, but doing exercise may help your fatigue. One study noticed that people with Crohn's and Colitis who exercise, even just a little bit during the week, feel less tired than those who do not exercise at all. Other studies have shown exercise programmes may help lower fatigue in people with Crohn's and Colitis. You do not have to push yourself too hard - even just a short walk or ten minutes of simple yoga may help. Have a look at our information on [living with Crohn's and Colitis](#) to see how you can become more active.

Looking after your mental health

If you're worried about your mental health, try to speak to your GP or IBD team. Some IBD teams have psychologists attached to their team who can help. In some areas of the UK, you can also self-refer to local psychological services. They can assess you and see what support you may need. We have further information on [mental health and wellbeing](#).

Some talking therapies, specifically Acceptance and Commitment Therapy (ACT) may help with psychological symptoms of Crohn's and Colitis. There have been some small studies suggesting psychological therapies may also help improve fatigue in people with Crohn's and Colitis.

Improving your sleep

If you're sleeping badly, it's worth checking that you are not having a flare-up. Symptoms like pain and needing to go to the toilet suddenly can easily disrupt sleep, so it's important to get these under control. Poor sleep has also been associated with early signs of inflammation. [Depression and anxiety](#) can also cause poor sleep.

Sometimes other things unrelated to your Crohn's or Colitis can worsen sleeping patterns. Sleep hygiene is a term used to describe healthy sleeping habits. You can find helpful tips about [sleep hygiene](#) from the NHS. This guidance is not specific to people with Crohn's and Colitis, but you may pick up some useful tips.

If you have tried other things and you still have poor sleep it may help to speak to your GP to rule out any other conditions that can affect sleep.

Medicines

If you're taking medicines that are linked to poor sleep or fatigue, such as **steroids**, you may want to speak to your healthcare team. They may be able to give advice on how to manage this or may even suggest changing to a different medicine. Always speak to your doctor or nurse before stopping a medicine. Stopping steroids suddenly can be dangerous.

Work and education

If you're having difficulty with work because of fatigue, or vice versa, it may help to look at our **employment guide**. This gives information on how Crohn's and Colitis can affect work, and what you can do if you're struggling. It may help for your employer to look at our **guide for employers** for further support and information.

Schools and universities can often work with students to help them cope with symptoms such as fatigue. They may be able to extend deadlines or give you extra time during exams. We have more information about school and education on our **page for young people**.

Other things that may help with fatigue

Some people find probiotics help them with their energy levels. However, there have not been any studies yet to see if probiotics help with fatigue in people with Crohn's and Colitis. Our **other treatments** page has further information on probiotics.

There have been some promising results showing electroacupuncture may help with fatigue. However, results are early and more research is needed.

Stopping smoking and reducing the amount of alcohol you drink may also help with fatigue.

Budgeting energy

Living with fatigue means living with a sense of low energy, and from day to day you may have to prioritise what you ‘spend’ that energy on. For example, if you have a birthday party you want to go to, you may find you need to take it easy the few days before and after the party. For some people, comparing fatigue to budgeting money can be a helpful way to describe fatigue to others.

“I found it quite easy to burn out without realising. It took me a while to adjust my expectations of what I would be able to do in a day between periods of remission and flare up”

Charles

Living with IBD Unclassified

Taking it easy and asking for help

Be kind to yourself. Knowing when to stop and take a rest can be difficult, but important. It may take a while to work out what you can and cannot do. And this can be frustrating.

Talking to others about your situation can help. Studies show that people with fatigue feel happier if their loved ones are aware and involved. There are tips on how to look after your wellbeing in our [mental health information](#).

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Will my fatigue ever go away?

You may find your fatigue is easily treated and goes away within a few months. This may be the case, for example, if you are found to have iron deficiency anaemia and are given a top up of iron. Or if you are having a flare-up, and medicines make you feel better.

However, it may be that you and your doctor cannot find a cause for your fatigue. Or you are given treatment but it doesn’t help your fatigue. We know that 4 in 10 people continue to have fatigue even when their disease is not active.

Fatigue, like other symptoms of Crohn’s and Colitis, can come and go. Sometimes you may feel well and other times not so well. The important thing is to be kind to yourself, taking each day at a time.

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Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information 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 and employment. We'll help you find answers, access support, and take control.

All our information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis, and treatment options.
- Provide information to help you live well with your condition.
- Help you understand and access disability benefits.
- Be there to listen if you need someone to talk to.
- Help you to find support from others living with the condition.

Call us on **0300 222 5700** or email helpline@crohnsandcolitis.org.uk.

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

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information or call the Membership Team on 01727 734465.

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Fatigue Edition 3.1

Last amended: September 2023

Last reviewed: April 2022

Next full review: 2025



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About our information

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers, and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements.
- You would like more information about the research on which the information is based.
- You would like details of any conflicts of interest.

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE** or contact us through the **Helpline: 0300 222 5700**.

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 information 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.