

# **Fatigue**

Living with a condition like Crohn's or Colitis can be tiring. But many people with these conditions also live with 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. It can affect each person differently and some may find it difficult to describe their symptoms.

This information is for anyone affected by Crohn's or Ulcerative Colitis who experiences fatigue or wants to learn more about it. Our information looks at:

- What fatigue is
- Possible causes of fatigue
- How to talk to others about how you feel
- Hints and tips on managing fatigue

In this information, where we refer to 'Colitis' we mean Ulcerative Colitis. Some people with Microscopic Colitis also experience fatigue. There is little research on fatigue in Microscopic Colitis, but this resource may still be helpful if you live with this condition.

Throughout this information, we give tips on managing fatigue from people living with Crohn's or Colitis. We collected these tips using an online survey in December 2024. Everyone is different, and you may find that some of these tips do not work for you or may not be relevant to your situation.

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# **Key facts about fatigue**

- Fatigue is extreme tiredness that does not go away with the usual amount of rest or sleep.
- Fatigue is a common feature of Crohn's and Colitis.
- During a flare-up, fatigue affects around 7 in 10 people with Crohn's or Colitis.
- When in remission, fatigue affects around 4 in 10 people with Crohn's or Colitis.
- There are many possible causes of fatigue.
- Many people with Crohn's or Colitis say fatigue is the most difficult symptom to deal with.
- There are ways to help manage fatigue and limit its impact on your life.

# What is fatigue?

Fatigue is very different from being tired. It's an unpleasant feeling of ongoing extreme 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. Some people may experience low energy or strength, or a feeling of heaviness.
- **Mental**. Some people may experience low motivation, poor concentration, a lack of alertness, or a feeling of 'brain fog'.



Both physical and mental.

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

"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** 

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.

For some people, it may come on quickly. You may do too much of an activity, and when you stop the fatigue suddenly comes on.

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 your fault 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** 



## How many people have fatigue?

If you have fatigue, you're not alone.

Around 7 in 10 people with Crohn's or Colitis experience fatigue during a flare-up.

Fatigue is also common when Crohn's and Colitis are not active. This is known as being in remission. Around 4 in 10 people have fatigue when their Crohn's or Colitis is in remission.

In general, fatigue is more common in Crohn's than it is in Ulcerative Colitis. Fatigue may also be more common, or more severe if you:

- Have previously had IBD surgery
- Are female
- Are experiencing depression or anxiety
- Are experiencing complications outside the gut, like joint or eye problems

There has been less research into fatigue and <u>Microscopic Colitis</u>, or fatigue and <u>Inflammatory Bowel Disease Unclassified</u>. However, studies so far suggest fatigue is a common symptom in 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

# How fatigue might affect your life

Our <u>2024 survey</u> shows that of all the ways Crohn's and Colitis can affect a person's quality of life, fatigue has the biggest impact.



Sometimes it may be hard to work out whether your tiredness is normal for you or not. It may even be someone else who 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 being active harder than you would expect. This could include things like sports, but also everyday activities, like household chores, or going food shopping.

On bad days, even things like showering or getting dressed may sometimes feel like too much, and walking to the bathroom may feel like a marathon. Sometimes you may feel fine exercising but notice it takes much longer to recover.

#### Social activities

Fatigue can sometimes make seeing friends and family difficult:

- You may find yourself cancelling plans or avoiding meeting up with people
- You may notice that concentrating and engaging in conversations is harder



- You may start to notice you stop doing things like going on holiday, seeing friends, or taking part in hobbies
- You may push yourself to do things but feel unwell afterward
- Other people may notice you seem withdrawn and not your usual self

All of these things might make you feel guilty for not wanting to be around people. If you can, talk to someone about what you're going through so they can find ways to support you. Talking to someone who understands can make a big difference. This may include friends, family or your GP. See our section on talking to others with fatigue.

#### **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, angry or experience low mood.

Coping with a long-term condition like Crohn's or Colitis can have a big impact on your mental health and wellbeing. You may feel as if you have lost some control over your life, or you may feel isolated or lonely. For some people, their fatigue may be associated with anxiety or depression. You can find out more in the 'looking after your mental health' section.

"Fatigue is a constant throughout my Crohn's journey and one that although it "comes & goes" with flares & general state of health it never truly goes away. Worrying about being fatigued when I have big events coming up can, in my experience, exacerbate the feeling of being fatigued."

Charlie

**Living with Crohn's** 



#### **Relationships**

You may notice fatigue impacts 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.

Our information on <u>sex and relationships</u> can help you think and talk about the effect your condition has on sex, intimacy and relationships.

## **Caring for a baby**

Caring for a baby can be difficult but caring for a baby while living with fatigue is an extra challenge. You can find helpful tips on feeling tired when caring for a baby on the <u>NHS</u> website.

Some people who are breastfeeding with fatigue may find certain positions difficult to maintain or may have latching issues. There are many different possible positions, and you can experiment with these to find a position that works well for you.

## **Looking after children**

Being a parent or carer with fatigue can be tough. You may find that you don't have the energy to play with your children or grandchildren in the way you'd like to, or you may need to cancel days out because you're too exhausted. Making sure that a child is dressed, fed and cared for can be tiring for anybody, but doing this with fatigue may feel like an impossible task.

Not being able to parent in the way you want to may come with a feeling of guilt. It can be difficult to deal with these feelings, especially if you have younger children who might not understand what you're going through. Our section on managing your fatigue gives you hints and tips to help you save energy in many different parts of your life.

Our <u>Meet our Crohn's and Colitis Cats story</u> is for younger children affected by Crohn's or Colitis, whether they have the condition themselves or know someone who does.



## **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

You may notice that fatigue impacts 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. To cope with this, you may find reducing your hours or changing how you work can help. Or, as a last resort, you may leave work altogether.

Our information on **employment** has further guidance and tips on how to manage work.

"I would always use to do too much, push through and then 'crash and burn', experiencing huge bout of fatigue and taking time off work. Now, I am more realistic with my life and plans, still having fun and factoring in rest."

Sophie

**Living with Crohn's** 



#### **Education**

For students, fatigue can make keeping up with work and exams hard. But being a student is not all about being academic. You may find that fatigue also affects meeting your friends, volunteering or sports.

If you're going off to university, it can be both exciting and daunting at the same time. You may be concerned about how you will be able to manage your fatigue while making friends and learning.

You can read other's stories on how to get the support you need in **our information for** students.

## Talking to others about fatigue

Living with fatigue may sometimes feel isolating. Being able to talk about what you're going through to someone who understands can make a big difference. A bit like pain, fatigue can be hard to explain to other people. People who do not experience fatigue may not understand how different it is from normal tiredness.

Our <u>Talking Toolkit</u> gives you tips on talking about your fatigue and how to have conversations about how you feel.

"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 experience fatigue in different ways. If you find it difficult to explain how you feel, try writing down some words that describe how it affects you. Or you may find it helpful to write down how it's affecting your life, such as:

- Have you stopped seeing friends?
- Are you not eating what you want to or 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?

## **Hiding how you feel**

It can be difficult to talk about fatigue. You may worry that people will not understand what you're going through. You may worry that people might judge you or think you're lazy. Many people living with extreme exhaustion try to brush off their fatigue, play it down or lie about the real reason for cancelling plans. Being honest about how you feel helps people understand what it's like to live with fatigue and support you better.

We asked people with Crohn's and Colitis to let us know how they described their fatigue. Here's what they said:

"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"

**Quotes from survey respondents** 





Talking about your symptoms can be difficult and may bring up unexpected emotions. If you're struggling, our helpline can help you find the support you need. Find out about the ways to get in touch with us and the ways we can help.

## **Letting your healthcare team know**

A lot of people with Crohn's and Colitis live with fatigue, but healthcare professionals do not often ask about it. Around 4 in 10 people are not asked about fatigue in their appointments. But when doctors ask about fatigue, Crohn's and Colitis patients are more likely to:

- Rate the quality of their care highly
- Report feeling more able to cope

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. You could:

- Ask your healthcare professional what tests can be carried out to look for the cause of your fatigue
- Ask if you need any blood tests to check for anaemia
- Check if any medicines you take could cause these symptoms?

Telling doctors and nurses how tired you are may not always ring the same alarm bells as other symptoms. But, ongoing fatigue that stops you from 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 think about words that describe how you are feeling. <u>Our appointment</u> <u>guide</u> can also help you communicate how fatigue and other symptoms impact 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

#### Tips from people in our community who live with fatigue:

- Don't hide your troubles. Some people don't realise how much of an impact fatigue
  can have. Keeping it bottled up won't help you and people won't know what help you
  need.
- If you're explaining how fatigue impacts you, try telling people how daily activities can affect you and what they do to your energy levels.
- Explain that fatigue is a symptom of IBD and not a mindset. It's important people know that you can feel fatigued even when other symptoms are being managed.
- Don't be 'brave' or 'soldier on'. Being honest is better in the long run.
- Try to advocate for yourself. Let people know when you're not in a position to do something.

# **Measuring fatigue**

Crohn's & Colitis UK helped to create the IBD Fatigue Scale, also known as the IBD-F. This can be used to rate how severe your fatigue is. It has been shown to be a helpful tool to measure fatigue levels in people with Crohn's and Colitis.

Our fatigue scale enables you to:

Assess your own fatigue and the impact it has on your life.



- Take along a completed fatigue scale to healthcare appointments. This can make
  it easier to talk about your symptoms and how they affect you.
- Assess whether changes in lifestyle are having any impact on your fatigue levels.
- Discuss fatigue with family, friends and employers.

Find out more about our **fatigue rating scale for Crohn's and Colitis**.

If you find it difficult to talk about fatigue, you may find it helpful to fill in the **questionnaire** and show the results to your healthcare team.

## The causes of fatigue

There are lots of ways that Crohn's and Colitis may cause fatigue. It may not always be one thing that causes your symptoms.

## **Inflammation and disease activity**

We know that fatigue is more common in people with active inflammation in the gut. It 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. It can also be caused by the chemicals released from inflammation. These chemicals 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 take in the nutrients your body needs. Poor nutrition, also called malnutrition, may also be caused by diarrhoea or not eating enough. 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 a vitamin this is called a deficiency. Iron deficiency is a common deficiency in Crohn's and Colitis and can lead to iron deficiency anaemia.

Fatigue may also be linked with low levels of:



- Vitamin B12
- Vitamin D
- Folate also known as folic acid or vitamin B9
- Thiamine also known as vitamin B1
- Calcium
- Magnesium
- Selenium

You can find out about eating well with Crohn's or Colitis in our information about food.

Speak to your GP or IBD team if you think you may have any deficiencies.

#### **Anaemia**

Anaemia is when you have low levels of healthy red blood cells in your body. Red blood cells carry oxygen around your body. Oxygen is one of the key ingredients that gives your 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 or have headaches.

You may be offered blood tests to check if you are anaemic.

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 1 in 3 people with Crohn's or Colitis have anaemia. But it's more common in people who are admitted to hospital with active disease. Around 7 in 10 people admitted to hospital with active Crohn's or Colitis have anaemia.

There are 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.

#### **Poor 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

- Symptoms in other parts of the body. People with symptoms in other parts of the body, like joint or eye pain, seem to have higher levels of fatigue. Symptoms in other parts of the body are known as extra-intestinal symptoms.
- Primary Sclerosing Cholangitis (PSC). This is a rare condition that affects around 1
  in 50 people with Inflammatory Bowel Disease. It causes inflammation of the bile
  ducts and can eventually damage the liver. The most common symptoms of PSC
  are itching and fatigue.
- Surgery. People who have had surgery for their Crohn's or Colitis also seem to have higher levels of fatigue.
- Irritable bowel syndrome (IBS). 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 living with Crohn's or Colitis. Fatigue has
  also been associated with IBS.
- Other immune-mediated conditions. 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 condition, like rheumatoid arthritis



or ankylosing spondylitis. People with these conditions also experience high levels of fatigue.

- Other conditions. Thyroid disorders, diabetes and kidney disease can all cause fatigue in the general population.
- Chronic fatigue syndrome (CFS). This is also known as myalgic encephalomyelitis
   (ME), and 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 medicines 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, which could also contribute to fatigue.

Anti-TNF medicines, such as adalimumab, golimumab and infliximab, are often reported to cause fatigue.

Most medicines may list tiredness as a side effect. Speak to your IBD team if you think your medicine might be making your fatigue worse.

#### **Poor sleep**

Many people with Crohn's or 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
- Needing to go to the toilet during the night
- Feeling or being sick
- · Side effects of medicines
- Depression, anxiety, or stress



Worries about your stoma leaking

## **Bacteria in the gut**

Early research suggests that the bacteria that naturally live in your gut, known as the gut microbiome, may be linked with fatigue.

Research has shown that people with Crohn's or 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 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 or Colitis seem to have smaller muscles and lower muscle strength than people without Crohn's or Colitis. This is likely due to many factors, such as 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 ways you and your healthcare team can try to help take control of your fatigue. In the sections below we give some tips on ways to help manage life with fatigue. What works for one person may not work for another, and your personal needs may affect which tips are most useful for you.



"I am a carer for my adult son who I would describe as paralyzed with fatigue and low energy on a daily basis. We take each day as it comes and he does what he can in bite-size pieces. Fatigue is a constant battle but can be managed. The key advice my son would give is listen to your body and manage your fatigue accordingly."

Mary

A carer for her son who lives with Crohn's

#### **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. By controlling inflammation and symptoms, such as pain, you may be able to reduce your fatigue.

Your healthcare professional may ask you to do some tests. You may be asked to have blood and poo tests. You may be sent for an endoscopy or a scan to check if your gut shows signs of active disease. Our information on <u>tests and investigations</u> 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 blood for anaemia or low levels of nutrients. However, not all nutrients can be tested easily. Your doctor may check your iron, zinc, 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. If your GP surgery or hospital offers personal health record services, you may see your test results in the NHS app. Even if all your blood tests are OK, it may help to feel involved in your care and to know the numbers.



#### **Treating anaemia**

If you have iron deficiency anaemia, you may be given iron, either with tablets or through a drip. This often helps fatigue.

If you are offered iron tablets, you may be given one tablet a day. Your healthcare professional may suggest you take this with vitamin C, such as a vitamin supplement or a glass of orange juice. Vitamin C is believed to increase the amount of iron your body absorbs. You should take your iron tablet with water or juice only. Do not take your iron tablet with milk. Milk may reduce how much iron your body can absorb. You may also be advised to avoid drinking too much caffeine, such as tea or coffee, as this may also make it harder for you to absorb iron.

Some people experience side effects when they take iron tablets. These can include diarrhoea, constipation or tummy pain. If you experience side effects, your healthcare professional may suggest you take a tablet every other day.

Some people may be offered an iron infusion. This is where iron is injected into the bloodstream at a steady rate over a period of time. You may be offered an iron infusion if:

- You have an iron deficiency and are having a flare-up
- Your Haemoglobin levels are very low, such as less than 10g/dL or 100g/L
- Taking iron by mouth, such as tablets or capsules, does not work well for you
- If you need medicines to help you produce more red blood cells. These medicines are known as erythropoiesis-stimulating agents (ESAs)

Some types of anaemia may be treated with vitamin B12 and folate.

In very severe cases of anaemia, a blood transfusion may be needed to treat your anaemia. A blood transfusion is a safe procedure where blood from someone else is put into your veins through a narrow tube.



## Other medicines for fatigue

Topping up your vitamin D may help your fatigue, but there is not much evidence for this. Vitamin D is good for your <u>bones</u>, and the government recommends everyone take it in the autumn and winter months.

There is some evidence that high-dose thiamine, also known as vitamin B1, may help reduce fatigue in people with Crohn's and Colitis. But more research is needed before this can become a routine treatment.

## **Medicines linked to fatigue**

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

## **Managing other symptoms**

If you're experiencing other symptoms that affect your energy levels, like incontinence or diarrhoea, you might want to look at our information on <u>managing symptoms</u>.

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 make changes in your day-to-day life and track whether these help your symptoms and your fatigue.

## **Attending medical appointments with fatigue**

Fatigue can make it difficult to get to and from medical appointments. It can also affect your ability to remember when an appointment is. The tips below can help you manage these appointments and help you get the best out of them.



## Tips from people in our community who live with fatigue:

- Ask if your medical appointments can be over the phone or a video call. This may be easier than an in-person meeting.
- Make life easier and write down important information, appointments and dates of blood tests in a diary or on a calendar.
- If possible, try to rest the day before a medical appointment. This could include cutting back on housework and daily chores.
- Try to prepare everything you need for a medical appointment the night before. This can help you feel less rushed and reduce stress on the day.
- If your GP is close by, ask if a friend or family member can take you. You could take a taxi, but this may not be an option for many people.
- Order your prescriptions to be delivered so you don't need to collect them.
- Always speak to the doctors about ongoing fatigue. It could be due to other issues, such as anaemia, vitamin deficiencies, or other things.
- Discuss your fatigue with your IBD team. There might be more ways for them to improve your treatment and help with your fatigue symptoms, even when other symptoms have improved.

#### Food and drink

There's no single diet that has 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. 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**.

It's suggested you eat regular smaller meals or healthy snacks throughout the day to help keep your energy up. You could try to eat something every three to four hours instead of several larger meals.



You may find certain foods trigger, worsen, or help your symptoms. However, changing your diet and cutting out certain foods may lead to some nutrient deficiencies. 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, helps with their fatigue. However, there is little evidence to support this. Some vitamin supplements can affect how medicines taken by mouth are absorbed, so try to let your healthcare team know if you are taking any. 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. Dehydration can make you feel tired, but this feeling may be unrelated to your fatigue. You may find drinking little and often easier than drinking lots in one go. If you're sick a lot or have 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 <u>dehydration</u> gives more details about this topic.

- Keep a water bottle and snacks near you for when you need them. You could put these by your bed or your sofa, or wherever you rest when you're fatigued.
- Drink regularly throughout the day to stay hydrated. You can find tips on staying hydrated on the NHS website.
- Eat as healthy as possible to help your body heal. This is not always easy when living with IBD.
- Eat meals that are easy to prepare. These could be quick meals, ready meals, frozen meals or you could use a slow cooker.
- Take advantage of good days by batch cooking. Divide the food into portions and freeze to help you when you don't have the energy to prepare a meal.
- Have your food delivered instead of shopping in-store. This will cost extra and may not be an option for many people.



- If you find eating larger meals challenging, try eating little and often.
- Try eating soft or blended food to make eating easier.

#### **Being active**

It may sound odd, but doing exercise may help your fatigue. Some studies have shown exercise programmes may help lower fatigue in people with Crohn's and Colitis.

If you're able to exercise, take it gently at first and build up your strength over time. Remember to be patient with yourself.

Some people with severe fatigue may not feel they can do any exercise. If you're feeling well enough, a small amount of exercise may help. You could try chair-based exercise. Have a look at our information on <u>living with Crohn's and Colitis</u> to see how you can become more active.

- If possible, try to get up and move around every now and then.
- Choose a time and activity that suits you and rest afterwards if you need to.
- If you have a dog, a walk could be good for both of you.
- Listen to your body. If it's too much then rest as much as you need to help you recover.
- Give yourself permission to go at a slower pace than you might usually.
- Exercise doesn't need to be strenuous, just do what your body is capable of. It could
  be stretching, a short walk, a few minutes of yoga or swimming. If you've got the
  energy, it can help.
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## **Looking after your mental health**

Speak to your GP if you're worried about your mental health. They may be able to refer you for support. In some areas of the UK, you may be able to refer yourself for support. You can find out more in our <u>mental health and wellbeing information.</u>

Some talking therapies like Acceptance and Commitment Therapy, known as 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.

- Set yourself small goals each day and tick them off as you complete them. This
  could include how many drinks to have, how many times to get up etc. Make sure
  you don't overdo it and make your goals realistic.
- Do something to make you feel refreshed, such as run a bath, take a shower or sit by an open window.
- Do things that are important and bring joy, this might be gardening, meditation,
  playing an instrument, knitting, jigsaw puzzles or playing video games. Never
  underestimate the power of dancing to 'bad' music to put a smile on your face. Even
  a finger dance and a head bop can help.
- Don't write the day off. If it's taken most of the morning to get out of bed, remember there's still time to have a good day. Do what you can with what you've got.
- At the end of each day, write down a few things you're grateful for or write about how you feel.
- Spend time in nature. Watch the birds, feel the sun on your face, get some fresh air, open a window, stand at your backdoor, go for a walk, whatever works for you. Look for beauty in the small things.
- If you need support, access formal mental health support or find a local support group. Find a therapist or counsellor who specialises in chronic illness.



Remember fatigue is part of your condition. It doesn't mean you are unfit or lazy.
 The way you cope with it is superhuman.

## Improving your sleep

If you're sleeping badly, it's worth checking that you are not having a flare-up. Poor sleep has also been associated with early signs of inflammation. Some symptoms, like pain or suddenly needing to go to the toilet, can easily disrupt sleep. Trying to get your symptoms under control may help you sleep better.

Sometimes other things unrelated to your Crohn's or Colitis can affect your sleep. Sleep hygiene is a term used to describe healthy sleeping habits. You can find helpful tips about <u>sleep hygiene</u> 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.

- Try to get plenty of sleep. Get an early night. It may not cure your fatigue, but not getting enough sleep could make you feel worse.
- Turn off your phone when you sleep so that you're not disturbed.
- Get ready for bed while you still have the energy.
- Nap if you need to. If you're worried about napping for too long and ruining your sleep, set an alarm and have a short nap.
- Try not to stress if you can't sleep. Get up and do something quiet for a little while and then try again later.
- Try drinking a bedtime tea before sleep or use a weighted blanket sometimes. Try to do things to wind down before bed.



#### **Work and education**

If you're having difficulty with work because of fatigue, or vice versa, it may help to look at our <u>employment guide</u>. This gives information on how Crohn's and Colitis can affect work, and what you can do if you're struggling. It may help your employer to look at our <u>guide for employers</u> 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 the challenges people face when going to university on our <u>student blogs page</u>.

Our supporting your child information has tips for parents on adjustments at school.

#### Tips from people in our community who live with fatigue:

- Try talking to your work about your symptoms. If you need to, ask for reasonable adjustments, such as reduced hours, working from home or working more flexible hours.
- If you can, think about early retirement or choosing a less stressful job. This may not be an option for many people.
- If you work from home, work from your bed.
- If you need to, seek financial support. Try applying for personal independence payment (PIP). This can help with money to support you with daily tasks or mobility.

#### **Budgeting energy**

Living with fatigue means you may have to prioritize what you use 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. For example: each day you're given a certain amount of energy to spend. Everything you do uses some up, such as getting dressed, having a shower, going for a walk. But since you start each day with a limited amount, you must decide how you want to 'spend' it.

"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** 

#### **Organising yourself and having a routine**

When you feel fatigued, everyday tasks can be difficult to manage. On good days, spending a little time creating a daily routine can mean you have less to think about on low-energy days. It may take a while to work out what you can and cannot do, but being organised can make a big difference and give you a sense of achievement.

- Create a routine for yourself to spread out regular tasks. This can make life more manageable. Make sure your routine is adaptable to how fatigued you feel. For example, if you go for a daily walk, go for a shorter walk on high-fatigue days.
- Try to manage how much energy you have for tasks. Save up energy or when you know you have something big coming up etc.
- Write a daily to-do list or have a planner to unload your mind. This can give you a
  sense of achievement and help you feel less overwhelmed. When creating this list,
  be kind to yourself and don't set unrealistic expectations.
- Don't be rigid with your to-do lists. Keep them as 80% must-do's, 20% nice-to-do's.



- If you haven't achieved what you wanted, roll it over onto your list for tomorrow.
- Work to your strengths. If you tend to feel less tired in the mornings or afternoons,
   try to take advantage of that time.
- Use reminders on a mobile phone, smart device or Al assistant for appointments or time to take medication. This can help to take some of the mental strain
- Create a fatigue kit or action plan when feeling less fatigued. This could include a
  favourite short walk 'playlist', things to watch on TV, food to eat, music to listen to,
  quick recipes.

## **Managing your home**

When you live with fatigue, jobs like cleaning, washing clothes or washing dishes can seem like an impossible task. For some people, it may be.

We're all different and have different priorities. It can be difficult to find a balance between what's right for your body and what you need to do to keep your home running. You might try a few things before you get that balance right but always be kind to yourself.

- See an Occupational therapist. They aim to improve your ability to do everyday tasks
  if you're having difficulties. Find out how to receive occupational therapy on the NHS
  website.
- It's OK not to get everything done. Prioritise you and the care you need over chores around the house.
- Do what you need to. Does all the washing up need to be done, or can you just wash the item you need?
- If you have a partner or housemate, talk to them about how you feel and how you
  can work together to sort the housework. Then prioritise what needs to be done and
  when.



- Have a 'not dirty' basket that you can throw your clothes at to avoid having them around the room.
- Only do the essentials and try to break tasks down into smaller chunks. For
  example, if you need to prepare a family meal for the evening, try to do little bits
  throughout the day between resting periods.
- Sit down if you need to iron.
- If you can afford it, get a cleaner or a robot vacuum. These can be expensive and may not be options for many people
- Think about where things are placed and the energy you spend trying to get them.
   Keep important items within easy reach.

#### **Socialising and events**

Living with fatigue can sometimes make it difficult to spend time with others. You may need to cancel plans and may feel like you're letting others down. Or you may feel even more exhausted after attending an event. Sometimes you may need to choose between what you want and what your body needs. It's also important that you don't feel isolated. Read our hints below on how to balance your fatigue and your social life.

- Give yourself permission to say no to social events. Learn to be open and honest about tuning down invites and explain why you can't make it. Those who mind don't matter, and those who matter don't mind.
- If there's something you want to do, try to limit your activities to save your energy.
- Space out your appointments, social events, etc. so that you have time to rest.
- Travel can be tiring, so invite friends and loved ones to yours, even if it's just to sit
  and watch TV, play video games or board games. If you're in your pyjamas, why not
  tell your friend to bring around theirs?
- It's easy to feel isolated when you live with fatigue, but if you don't have the strength to see anyone, keep in touch by calling or messaging them.



- Social media can help you find other people who are going through something similar.
- Factor in rest times or rest days so that you can fully enjoy the plans you do have.
- Be realistic about how long you can socialise for and know when to go home. Tell
  friends that you may only visit for a short time. Reassure them that it's your fatigue
  and nothing personal. If you're able to stay longer then great, but at least it removes
  any pressure or expectation.
- Try not to let concerns about being fatigued stop you from making plans. Explain
  what you find difficult and what adjustments can help to make it easier for you to
  still join in. Make the plans anyway and if you have to cancel on the day, people will
  understand.
- Ask friends or family to ring first before they come over. That way they can make sure you're up for a visit or are not resting.

## **Travelling**

Whether it's by plane, train or coach, travelling can sometimes feel like a daunting task. Being organised is a great way to take the stress out of travel. The points below can support you in getting to the places you need to go.

- When packing, be mindful of how heavy your bag will be. It's a lot easier to wheel a suitcase than carry a bag.
- Build in enough travel time buffers so you aren't rushing. This might include extra time to change train or bus, or time to walk from one place to another.
- If travelling by car, take a blanket so you can have a nap during a rest stop. Trains and planes are also a great place to take a nap.
- Stress can make you feel tired. Reduce your stress by knowing where the toilets will be. Don't forget to pack your radar key, can't wait card, medicine and a change of clothes.



- When at the airport, see if there are quiet rooms, sensory rooms or family rooms available nearby for you to visit and rest in if needed.
- Don't expect yourself to travel for hours and then go straight into something energetic. Travel the day before an event if you can, rest, then do your activity. Factor in time to rest afterward too.
- Know where you're going, where parking is or how far the train station is. Planning in advance may be more helpful than looking for where a place is when you're fatigued.
- Walking aids, such as sticks, crutches or a wheelchair may help conserve energy when travelling.

#### **Asking for help**

Talking to others about your situation can help. Studies show that people with fatigue feel happier if their loved ones are aware and involved.

- Learn to say yes to offers of help. Don't feel you have to cope all alone.
- Learn to actively ask for help. It takes courage to ask for help sometimes. People
  who care about you want to help and giving them something to do can make them
  feel helpful.
- Make sure loved ones know that it's OK for them to offer to help.
- Be specific about telling people what you need and how they can help you.
- Remember to show your appreciation to those who support you. It's the right thing
  to do and goes a long way to maintain that support.
- It's easy to do, but don't feel you need to apologise for things you can't do. You
  would if you could.



## Other things that may help with fatigue

Some people say they find probiotics help them with their energy levels. However, there have not yet been any studies 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 studies showing electroacupuncture and other medicines may help with fatigue. However, more research is still needed.

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

## Will my fatigue ever go away?

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.

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 iron supplements. 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. Learning to live with fatigue can be difficult but we're here to help you find the support you need.

# How to support someone with fatigue

Whether you're a friend, family member or partner, the suggestions below may help you understand how you can support someone with fatigue.

#### Tips from people in our community who live with fatigue:

Show you're thinking of us and want to see us.



- Include us in plans, even if we didn't make it last time or the last four times, it makes us feel included. Even better, make plans with us.
- Join us on walks or for sofa dates with blankets.
- If you invite us to something, let us know there's no pressure if we need to cancel our plans due to our symptoms.
- Don't take our cancellations personally. We would join you if we could.
- We probably feel guilty about cancelling plans, as well as not doing housework or not living up to others' expectations.
- Know when we might want some space.
- Support us with daily tasks. Offer to do specific things instead of asking if we need anything. It can be taxing to think of things to ask for.
- Bring us hot water bottles and our favourite snacks.
- Try to understand where we're coming from.
- Don't compare us to other people you know who also have fatigue. It can affect people in different ways.
- Feel free to ask questions. Talk to us about what we're going through.
- Don't be surprised if we look OK. Fatigue affects how we feel and not necessarily how we look.
- Recognise and be compassionate that fatigue can also affect mood and our ability to think.
- Be patient with us.
- Walk slowly with us.
- Don't expect sleep to solve our fatigue.
- Don't confuse our fatigue with laziness.
- Try to understand the difference between fatigue and being tired. They are very different. Understanding this difference can go a long way to supporting us.
- Allow us to rest or sleep when we need it.
- Know we are grateful for you and your support.



## Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our website.

## **Helpline service**

Our helpline team provides up-to-date, evidence-based information. You can find out more on our <u>helpline web page</u>. Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can help by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. You can also visit our <u>livechat service</u>. Lines are open 9am to 5pm, Monday to Friday, except English bank holidays.

You can email <a href="mailto:helpline@crohnsandcolitis.org.uk">helpline@crohnsandcolitis.org.uk</a> at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

#### **Social events and Local Networks**

You can find support from others in the Crohn's and Colitis community through our virtual social events. There may also be a Local Network in your area offering in-person social events. Visit our <u>Crohn's and Colitis UK in your area webpage</u> to find out what is available.



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

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the Crohn's & Colitis UK Forum.

#### Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See <a href="our membership webpage">our membership webpage</a> for more information. Or you can call the Membership Team on **01727 734465**.

#### **Crohn's & Colitis UK Medicine Tool**

Our **Medicine Tool** is a simple way to compare different medicines for Crohn's or Colitis. You can see how medicines are taken, how well they work, and what ongoing checks you need. You can find out more on our **Medicine Tool webpage**.

The Medicine Tool can help you:

- Understand the differences between types of medicines
- Explore different treatment options
- Feel empowered to discuss medicine options with your IBD team

Always talk to your IBD team before stopping or changing medicines.

#### About Crohn's & Colitis UK

Crohn's & Colitis UK is a national charity, leading the fight against Crohn's and Colitis. We're here for everyone affected by these conditions.

Our vision is to see improved lives today and a world free from Crohn's and Colitis tomorrow. We seek to improve diagnosis and treatment, fund research into a cure, raise awareness and give people hope and confidence to live freer, fuller lives.



Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465**. Or you can visit **our website**.

#### **About our information**

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on our website.

We hope that you've found this information helpful. Please email us at <a href="mailto:evidence@crohnsandcolitis.org.uk">evidence@crohnsandcolitis.org.uk</a> if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- 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 you can contact us through the Helpline on 0300 222 5700.

We do not endorse any products mentioned in our information.

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