



INFORMATION SHEET

FATIGUE AND IBD

INTRODUCTION

Many people with Ulcerative Colitis and Crohn's Disease experience fatigue, which affects each person differently. This information sheet describes the fatigue that may occur with Inflammatory Bowel Disease, explains what may cause it, and suggests possible ways to reduce it. Much of the information is based on results from the four-year Crohn's and Colitis UK Fatigue in IBD study.

“

Just feeling very, very weary, and no inner energy...I'm "bone weary" is the old way of describing it.

”

Fatigue in IBD study participant

WHAT IS FATIGUE?

Fatigue can be described as an overwhelming sense of continuing tiredness, lack of energy, or feeling of exhaustion that is not relieved after rest or sleep. It is far more than the ordinary and usual tiredness that anyone may feel after they have done a lot of physical or mental activity. For people with IBD, fatigue can feel physical (a lack of energy or strength), mental (a lack of motivation, concentration or alertness) or a combination of the two.

Fatigue can be very unpredictable, varying from day to day or even hour to hour. It can come on suddenly with no warning. People sometimes describe it as like 'hitting a brick wall'.

HOW COMMON IS FATIGUE IN IBD?

Fatigue in IBD is very common – over three-quarters of people experience fatigue during an IBD flare-up.

There doesn't seem to be a major difference in the levels of fatigue between people with Ulcerative Colitis and people with Crohn's. However, some research suggests that fatigue may be more common in women, and may be worse in people with Crohn's.

Many people find that their fatigue improves as their IBD improves. For some, there can be a time lag of weeks or months before they regain their normal energy levels. Sometimes the fatigue doesn't go away even when other IBD symptoms are under control. Fatigue continues to affect two in every five people whose IBD is in remission.

WHAT CAUSES FATIGUE IN IBD?

There are many factors that have been associated with fatigue in IBD. It is likely that these factors influence each other, so you may find that a combination could be contributing to your fatigue.

Inflammation

During a flare-up, fatigue may be caused by the body's response to inflammation and illness. Chemical signals that are produced during inflammation act directly on the brain to cause sickness behaviours – such as lack of motivation, tiredness and loss of appetite.

Pain

Pain is a common symptom for people with IBD and may be caused by a number of factors, including inflammation, blockages and bloating in the gut, along with pain caused by manifestations of IBD in other parts of the body, such as arthritis. In some cases, pain will remain during periods of remission. Dealing with pain can be draining. Pain may contribute to fatigue through poor sleep quality, reduced physical activity and emotional and psychological distress.

Nutritional deficiencies

Nutrient and vitamin deficiencies in people with IBD may be caused by diarrhoea, a loss of appetite or poor absorption through the inflamed gut wall.

Anaemia, a common complication of IBD, may worsen fatigue. People with anaemia carry less oxygen in their blood, which can mean they easily become exhausted.

In people with IBD, anaemia can occur due to:

- a persistently low level of haemoglobin, a protein in red blood cells that carries oxygen around the body. This can result from poor absorption of iron in the gut
- low numbers of red blood cells, which may be caused by loss of blood from the inflamed wall of the gut, or by deficiencies in vitamins B12 and/or folate

Low vitamin D levels may also contribute to fatigue. Vitamin D is important for keeping your bones, muscles and immune system healthy.

Emotional stress/psychological disorders

Anxiety, depression and stress are consistently associated with fatigue in people with IBD – however it is not clear whether anxiety, depression or stress cause fatigue, or are a result of fatigue. Emotional and psychological stress can trigger inflammation and pain, and as described above, these factors may contribute to fatigue.

Medication

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

Disturbed sleep

Poor sleep quality may be the result of pain or having to use the toilet multiple times during the night.

Other possible causes

It is unclear why fatigue doesn't always get better when the IBD does, and why it can continue even during remission.

In some cases, people may think they are in remission because they do not have any obvious symptoms of IBD, such as diarrhoea or bleeding. But they may still have some inflammation in the wall of the gut that could be causing their fatigue.

“
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

In the Crohn's and Colitis UK Fatigue in IBD study, available at www.fatigueinIBD.co.uk, a number of other factors were suggested as possible causes for fatigue. These included:

- Diet and alcohol
- Being overweight or underweight
- Other health problems
- Extremes of weather
- Lack of support or understanding

Any of these factors may lead to fatigue. However, in some people there is no obvious explanation.

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

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

“Go to work, barely get through the day and then coming home and then just crashing out, and I couldn't do anything because I didn't have the energy.”

Fatigue in IBD study participant

“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

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HOW DOES FATIGUE AFFECT PEOPLE WITH IBD?

Fatigue can affect many aspects of life. Some people find it difficult to perform everyday functions when their IBD is active, because of both bowel symptoms and fatigue. Fatigue may affect the lives of people with IBD in many different ways:

- **Physical Activity**
Low energy levels can make it very hard to take part in physical activities, such as sport. Some people find they don't have the energy to carry out everyday tasks such as driving, housework or collecting the children from school. On very bad days, even walking from one room to another may require great effort.
- **Memory and concentration**
Some people find that fatigue makes it difficult to think logically. You may find that it can affect your concentration and memory. When you are very fatigued, you may feel you cannot speak properly, and may stumble over your words. Some people call this 'brain fog'. See **Talking about fatigue** below.
- **Social Activities**
Unpredictable fatigue can make it difficult to take part in social activities. This may mean that you refrain from going on holiday, travelling, socialising, or taking part in hobbies or interests.
- **Emotions**
Fatigue can have an effect on your emotions. If you can't do as much as you would like, you may feel frustrated and angry. Some people feel isolated and lonely if they find it difficult to socialise with friends. This can lead to low confidence and depression. You may find it helpful to discuss your feelings with a counsellor. To find out more, see our information sheet **Counselling for IBD**.
- **Relationships**
Some people find that fatigue has a negative effect on their relationships with partners, friends and family. For example, some people may feel that,

“ Sometimes I don’t realise I have been suffering from fatigue until my energy levels have returned to normal and I look back. ”

Jo, age 50, diagnosed with Ulcerative Colitis in 1999

“ I think there can a bit of a stigma attached to fatigue where people might struggle through it not wanting to admit to it for fear of being seen as lazy. ”

Shirley, age 39, diagnosed with Ulcerative Colitis in 1993

“ I think my family are very supportive and so are my friends, because I’ve told them how I feel...It’s up to us to tell them how we are feeling. ”

Fatigue in IBD study participant

because their condition cannot be seen, their family and friends don’t appreciate how fatigued they are. You may find that you feel guilty if your partner or family have to do extra things to help, or if they miss out on doing things with you. Being open and honest about your condition may be helpful. If fatigue is having an impact on your sex life, you may find our information sheet **Sexual Relationships and IBD** helpful.

• **Work and education**

Fatigue can affect employment and education. Some people with fatigue may be able to manage a full-time job, while others may struggle with such a commitment. Some experience fatigue so strongly that they have to give up work. Working part-time or reducing the number of hours worked each day can sometimes help manage fatigue, but this might have financial implications. Our information sheet, **Employment and IBD: A guide for employees** provides more information on your options and how you might be protected by law.

Students with fatigue may find studying difficult, and may worry that fatigue will limit their achievements and job aspirations. Schools and universities can often work with students to help them cope with periods of IBD-related fatigue, such as setting extended deadlines or giving extra time during exams. See **Students with IBD: A guide for students** for more information.

TALKING ABOUT FATIGUE

It can be difficult to discuss fatigue and to explain the problems it causes. You might find it difficult to talk to your doctor about your fatigue, and therefore miss out on receiving help.

During the Crohn’s and Colitis UK Fatigue in IBD study, people with IBD used some of the following words to describe their fatigue:

- Brain fog
- A big black hole
- Being woozy or fuzzy
- Zombie mode
- Overwhelming heaviness
- Just shattered
- Completely wiped out

You may find it helpful to use some of these descriptions when you are talking to your healthcare team.

Some doctors and nurses are not aware how much fatigue can affect people with IBD, so they may not ask about it during an appointment. Fatigue is not a personal failing, and is nothing to be embarrassed about. It’s important that you discuss all of your symptoms and concerns with your doctor or IBD team. Of course, telling doctors and nurses you are tired doesn’t ring the same alarm bells as saying you have an immediately dangerous symptom. But, living with persistent fatigue is unacceptable, so you may have to push more than usual to ensure you get the proper care you need.

“ There’s a whole range of symptoms that employers, GPs, family, should be aware of as a result of your condition. ‘Tiredness’ is just one of them.”

—
Fatigue in IBD study participant

MEASURING FATIGUE

The Crohn’s and Colitis UK Fatigue in IBD study, funded by the Big Lottery Fund, led to the creation of a new IBD Fatigue Scale to measure the severity and impact of fatigue. You can find this at www.fatigueinIBD.co.uk/questionnaire. If you find it difficult to talk about fatigue, you may find it helpful to print the questionnaire and show it to your healthcare team.

There is also a checklist you can use to consider possible causes of your fatigue, in order to make sure nothing is overlooked. You will be able to fill in some items yourself, but for others you will need a doctor or nurse to give you the information. You can find the checklist at www.fatigueinIBD.co.uk/checklist.

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WHAT CAN I DO TO REDUCE MY FATIGUE?

There are a range of actions you can take to reduce or manage your fatigue.

The first and most important thing to do is to ask your doctor or IBD nurse to check that you do not have active IBD. This might be done with a blood test or stool test. If your IBD is active, then you will need treatment to see whether your fatigue improves as your IBD improves. This may mean changing the dose or type of medicine that you are taking. You should also speak to your doctor if you think your medication may be causing your fatigue, as they might be able to adjust the dose or find an alternative medicine.

If your IBD is in remission, you could ask for a blood test to check for anaemia, iron stores, vitamin B12, and other chemical or nutrient deficiencies.

Those experiencing emotional or psychological stress should speak to their GP or IBD team about accessing specialist support to help cope with this. Research has shown that counselling or ‘talking therapies’, such as cognitive behavioural therapy, can reduce stress and depression, and improve quality of life in people with IBD – and may also be beneficial in improving fatigue. For more information on the different types of counselling and how it may help you, see our information sheet **Counselling and IBD**.

There is some evidence that low to moderate intensity physical activity may reduce IBD fatigue. You could try gradually to increase the amount of physical exercise you do, while being careful not to overdo it. This can be simple activities, such as walking rather than catching the bus for short journeys, or going to exercise classes. It is important to achieve the right balance between doing too much and exhausting yourself, and not doing enough to make a difference. You might need to build up your activity level slowly over several weeks. See our booklet **Living with IBD** for tips on exercising with IBD.

If you smoke, stopping smoking can also help to reduce IBD fatigue. You may find our information sheet **Smoking and IBD** helpful.

If pain is contributing to your fatigue, you may wish to discuss pain management strategies with your IBD care team. There are a number of options that may help with pain in IBD, many of which have already been mentioned above as ways to tackle fatigue. These include drug treatments, exercise or physical therapy, stopping smoking and counselling.

For more information on how to increase your physical activity, or for advice on stopping smoking, visit www.nhs.uk/livewell.

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

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

CAN CHANGING MY DIET REDUCE MY FATIGUE?

Diet may also play a part in causing IBD fatigue, especially if you aren't receiving the amounts of calories and nutrients that are right for you.

There are many foods that may help alleviate various deficiencies, including vitamin B12, iron, folate and vitamin D, which is also synthesised in the skin during exposure to sunlight. Your doctor, IBD team or dietician can offer advice. For information on nutritional supplements such as iron, folic acid (a synthetic form of folate), vitamin B12 and others, you may want to read our information sheet **Other Treatments for IBD**.

Some people have found that taking other supplements, such as omega-3 oils (found naturally in oily fish and some other foods) improves their fatigue. However, there is little scientific evidence to support this. Check with your IBD team before taking any supplements or making major changes in your diet.

Some people find that during a flare-up they cannot tolerate certain foods. During remission, you should try to eat as balanced and healthy a diet as possible. Foods containing carbohydrates are a major source of energy. There are two types of carbohydrate – simple and complex. Foods containing complex carbohydrates (such as cereals or porridge) can provide you with longer-term energy. Foods containing simple carbohydrates (such as sugary sweets, cakes and biscuits) provide quick bursts of energy, but this energy only lasts a short time.

Although there is currently little scientific evidence, some people find that following a gluten-free diet reduces their fatigue.

Eating smaller meals and healthy snacks more frequently, rather than larger meals less often, may help you keep your energy levels up throughout the day. You could try eating every three to four hours to see if this helps your fatigue.

For more information about how to manage a healthy diet, see our booklet **Food and IBD**.

IS THERE ANYTHING ELSE I CAN DO TO REDUCE MY FATIGUE?

There are a variety of other ways in which people with IBD help themselves manage fatigue, for example:

- Frequent breaks and rest
- Good-quality sleep
- Complementary and alternative therapies such as mindfulness, acupuncture, yoga or homeopathy
- Physiotherapy and exercise
- Flexible working hours
- Planning ahead
- Reducing stress

Two further points to remember are to prioritise the demands on you, and to pace yourself.

“

I would have a rest in the morning and a rest in the afternoon. And that was how I got through the day. ”

Fatigue in IBD study participant

What works for some people may not work for others. Learning more about your body, and what may trigger your fatigue, can be helpful.

Talk to your doctor or nurse about your fatigue, and explore methods that might help you, rather than simply accepting it and missing out on support that is available. There are many methods – from resting to exercising – that you can try yourself to discover what works for you. If you need further help, your healthcare team may also be able to refer you to other services such as counselling or specialist chronic fatigue services.

FURTHER HELP

Fatigue Microsite
www.fatigueinIBD.co.uk

NHS Live Well
www.nhs.uk/livewell

HOW WE CAN HELP YOU

We offer more than 45 publications on many aspects of Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. You may be interested in our comprehensive booklets on each disease, as well as the following publications:

- Living with IBD
- Counselling for IBD
- Food and IBD

All publications are available to download from www.crohnsandcolitis.org.uk. The complete list is here: www.crohnsandcolitis.org.uk/about-inflammatorybowel-disease/quick-list.

Health professionals can order some publications in bulk by using our online ordering system, available from the webpage above.

If you would like a printed copy of a booklet or information sheet, please contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease.

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- help you to find support from others living with the condition

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

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

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ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 35,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how, call **01727 734465** or visit www.crohnsandcolitis.org.uk

