



INFORMATION SHEET

FATIGUE AND IBD

INTRODUCTION

Many people with Ulcerative Colitis (UC) and Crohn's Disease - the two main forms of Inflammatory Bowel Disease (IBD) - suffer from fatigue. This information sheet explains what IBD fatigue is, what may cause it, and possible ways of reducing it.

Much of the research in this information sheet is based on results from the Crohn's and Colitis UK study funded by the Big Lottery Fund. The quotes throughout the information sheet are also taken from this study. More details about the study can be found at the end of this information sheet.

“

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

”

WHAT IS FATIGUE?

Fatigue can be described as an overwhelming sense of continuing tiredness, lack of energy, or feeling of exhaustion which is not relieved after rest or sleep. It is far more than the ordinary and usual tiredness that anyone feels after they have done a lot of physical or mental activity.

Fatigue can be very unpredictable, vary day to day, or even hour by hour. It can come on very suddenly with no warning. People sometimes describe this feeling 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 does not seem to be a major difference in the levels of fatigue between people with UC and people with Crohn's. However, some research suggests that fatigue may be worse in people with Crohn's.

Many people find that their fatigue improves as their IBD improves. However, for some, there can be a time lag of weeks or even months before they regain their normal energy levels. Sometimes the fatigue does not go away even when the IBD seems to be completely under control. Fatigue continues to affect over 2 out of 5 whose IBD is in remission.

WHAT CAUSES FATIGUE IN IBD?

There are many factors which may contribute to fatigue in IBD.

During a flare-up, fatigue may be caused by the body's response to inflammation and illness, combined with

- exhaustion
- disturbed sleep
- pain
- and anxiety.

Anaemia, a common complication of IBD, can add to fatigue.

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

One possibility may be that some people who think they are in remission and do not have any symptoms of IBD (such as diarrhoea or bleeding), may still actually have some inflammation in the wall of the gut, which could be causing their fatigue.

If your IBD is completely in remission, then anaemia may be contributing to your fatigue. Some people may have a persistently low level of haemoglobin in their blood, often caused by blood loss in stools, or low levels of iron or vitamins, which can mean they get exhausted easily.

In the Crohn's and Colitis UK Lottery study, a number of other factors were suggested by people with IBD as possible causes for their fatigue. These included:

- Diet and alcohol
- Being overweight or underweight
- Other health problems
- IBD medication, in particular steroids
- Sleeping problems
- Pain
- Extremes of weather
- Stress
- Emotions such as depression and anxiety
- Lack of support and understanding.

Any, or a combination, of these factors may lead to fatigue. However, some people have no explanation for 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.”

HOW DOES FATIGUE AFFECT PEOPLE WITH IBD?

Fatigue can have an effect on all aspects of life. Some people find it difficult to function at all when their IBD is active, both because of bowel symptoms, and also fatigue. Research and surveys suggest that fatigue may affect the lives of people with IBD in many different ways:

“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.”

“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.”

“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.”

- **Physical Activities**

The low energy levels caused by fatigue can make it very hard to take part in physical activities such as sport. Some people find that they do not even 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 can be too much.

- **Memory and concentration**

Some people find that fatigue can make 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 the 'brain fog'. See **Talking about fatigue**.

- **Social Activities**

Unpredictable fatigue can make it very difficult to take part in social activities. This may mean that you find it difficult to go on holiday, travel, socialise, or even take part in hobbies or interests.

- **Emotions**

Fatigue can have an effect on your emotions. If you cannot do as much as you would like, you may feel frustrated and angry. Some people may feel isolated and lonely if they find it difficult to get out and socialise with friends. This can lead to depression and low confidence.

- **Relationships**

Some people find that fatigue has a negative effect on their relationships with friends and family. For example, some people may feel that, because their condition cannot be seen, their family does not 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 together. Talking about this may be helpful in this sort of situation.

- **Work and education**

Fatigue can have a direct effect on employment and education. Whereas some people with IBD fatigue may be able to manage a full time job, others may struggle with such a commitment. Some experience fatigue so badly that they have to give up work. Working part time or reducing the number of hours worked can sometimes help manage fatigue. However, this can have major financial implications.

Students with fatigue may find studying difficult, and may worry that their fatigue has limited their achievements and job aspirations.



TALKING ABOUT FATIGUE

One of the key difficulties with fatigue is that it can be difficult to discuss and explain it as a problem. This can mean that you may find it difficult to talk to your doctor about your fatigue, and therefore may miss out on receiving help.

During the Crohn's and Colitis UK Lottery 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 health care team.

Some doctors and nurses are not aware how much fatigue can affect people with IBD, so may not ask about it during an appointment. If you do suffer from fatigue, you should make sure you do tell your IBD team.

“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.”

MEASURING FATIGUE

A study funded by the Big Lottery Fund has developed a new IBD Fatigue Scale that can measure the severity and impact of fatigue on people with IBD. You can access this questionnaire at www.fatigueinIBD.co.uk. If you find it difficult to talk about fatigue, you may find it helpful to print the questionnaire off and show it to your health care team.

There is also a checklist that you can use to check for possible causes of your fatigue, in order to make sure nothing has been forgotten. Some of the things on the checklist you will be able to fill in yourself, but for others you will need a doctor or nurse to give you the information. You can also find information about the checklist at www.fatigueinIBD.co.uk.

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, most important, thing for you to do is to ask your doctor or IBD nurse to check that you do not have active IBD. This could be done by a blood test or stool test. If your IBD is active, then it needs treating to see if the fatigue improves as your IBD improves. This may mean changing the dose or type of medicine that you are on.

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. If you are iron deficient, your doctor may prescribe iron supplements.

Some of the drugs used to treat IBD can cause fatigue in some people. Your doctor or IBD nurse may be able to adjust the dose or find a possible alternative medicine.

There is currently little evidence on other possible ways of reducing IBD fatigue. However, in other conditions, such as cancer, exercise has been found to help reduce fatigue. It is possible that this may help IBD fatigue. You could try gradually increasing the amount of physical exercise that 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 gym sessions/ classes. It is important to get the balance right between doing too much and exhausting yourself, and not doing enough to make a difference.

CAN CHANGING MY DIET REDUCE MY FATIGUE?

Diet may also play a part in causing IBD fatigue, especially if you are not receiving the correct amount of calories and nutrients.

It is important to aim for a balanced nutritious diet, if possible. Some people find that during a flare-up they cannot tolerate certain foods. However, during remission it is important to try and eat as balanced and healthy a diet as possible. For more information about this, see our booklet: **Food and IBD**.

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 short-term bursts of energy.

There is some evidence that foods rich in omega 3 natural oils (such as oily fish) may help fatigue in other conditions. Some people have found vitamin and mineral supplements to be helpful. Check with your IBD team before taking any supplements.

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

Recent research has found that some people do find ways to help them manage their fatigue. Examples of things which people with IBD have found useful to reduce their fatigue include:

- Frequent breaks and rest
- Good quality sleep
- Alternative therapies such as acupuncture, yoga or homeopathy
- Physiotherapy and exercise
- Flexible working hours
- Planning ahead and reducing stress.

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

FATIGUE AND IBD

In summary, learning more about your body, and what may trigger your fatigue can be helpful.

Another key point to remember is to prioritise your time. It is particularly important to pace yourself.

However, also remember that everybody is different, so what works for some people may not work for others.

Talk to your doctor or nurse about your fatigue, and discuss things which may help you, rather than simply accepting it and missing out on any support that is available.

FURTHER HELP

Fatigue Microsite
www.fatigueinIBD.co.uk

HOW WE CAN HELP YOU

We produce **over 40 information sheets, booklets and guides** about all aspects of IBD which are available to download for free on our website:
www.crohnsandcolitis.org.uk

We run confidential support services for anyone affected by Inflammatory Bowel Disease.

Our **Information Service** is staffed by a team of trained Information Officers and provides callers with clear and balanced information on a wide range of issues relating to IBD. Call **01727 734 470** or email **info@crohnsandcolitis.org.uk**

We also run the **Crohn's and Colitis Support Line**, a supportive listening service provided by trained volunteers who are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD. **Call 0121 7379 931.**

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the **Information Line: 01727 734 470**.

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 28,000 members and 50 Local groups throughout the UK. Membership costs £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 or 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



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