

Chest
Heart &
Stroke
Scotland



LONG COVID FATIGUE



ESSENTIAL GUIDE

This Essential Guide is about managing fatigue if you have Long Covid.

It explains:

- what Long Covid is
- what fatigue is
- what you can do to help manage your breathlessness
- where to get additional advice and support.



This document may not contain the latest information. For regular updates, visit www.nhsinform.scot

What is Long Covid?

Many people recover quickly from COVID-19, but some may take longer to get better. When the symptoms are ongoing for 12 or more weeks, this is referred to as Long Covid.

Whether or not you develop Long Covid does not seem to be linked to how ill you were when you first get coronavirus or if you were hospitalised because of it. People who had mild symptoms of coronavirus at first can still develop Long Covid.



Long Covid and fatigue

The most common symptom of Long Covid is fatigue, which has been reported by over half of people who have had COVID-19.

Fatigue is a condition of complete physical and mental exhaustion. This is not just “feeling tired” - although tiredness is part of fatigue, it also includes a range of other symptoms, described overleaf. Fatigue is not “all in your head” – it has effects throughout the body.

It is thought that fatigue in Long Covid occurs because your immune system is overworked by the virus, which affects the way your body processes and produces energy. There may also be a link with chronic inflammation in the body. Long Covid fatigue may be temporary, but may also lead to a longer-term condition called “Post-Viral Fatigue” or “Chronic Fatigue Syndrome”.

What does fatigue feel like?

Fatigue affects everybody differently, and may feel different to you at different times, depending on things like your mood, stress, time of day, or general health. Some common symptoms include:

- Tiredness and lack of energy, which doesn't go away no matter how much you sleep
- Sleeping too much or being unable to get to sleep properly
- Headaches, body aches, and stiffness
- Dizziness or unsteadiness, especially when standing up
- The feeling of a weight pressing down on you, or of your limbs being very heavy
- Brain fog (see next page)

Brain fog

“Brain fog” is not a single symptom, but is a general term for the effects which fatigue can have on thinking, concentration, and memory. It’s called brain fog because people often describe it as feeling like their mind is “clouded” or “fogged up”. Brain fog can be present all the time, or it can come and go.

The feeling can vary a lot, but may include:

- Trouble concentrating
- Difficulty finding words or communicating
- Forgetfulness
- Slowed reactions and slower thinking
- Head “stuffed-up” or “full of cotton wool”
- Blurred or unfocused vision
- Becoming overwhelmed or struggling to process what you see and hear

Brain fog is often the most obvious symptom of fatigue. The best way to manage it is to avoid fatigue triggers, but there are also things you can do to prepare for periods of brain fog:

Keep notes of important information, so you can remember it later.

Forgive yourself. Remember it’s okay to make mistakes or to take longer on something than you might normally.

If possible, take breaks or do easy work during times when your brain fog is bad. It may help to keep a list of “easy” tasks you can do.

Talk to the people around you and explain that sometimes you may find it hard to think or to process information.

Chest Heart & Stroke Scotland produces a wallet card to explain brain fog quickly to those around you. Find it at **chss.org.uk**



Understanding your fatigue

Fatigue is a very individual thing, and it's important to get to know how your fatigue works - what triggers it, how it feels, and whether there's a common pattern to it.

Some things to consider might be:

Time of day – do you find yourself particularly tired first thing in the morning, or is it worse as the day goes on?

Trigger activities – do certain activities, such as exercise or thinking very hard, make your fatigue consistently worse?

Food and drink – do you feel more fatigued when you haven't eaten in a while, or when you're very full?

Season – is your fatigue worse in the winter?

Managing your fatigue

While there is no reliable single cure for fatigue, the symptoms can be managed. Many people find that, when they manage their fatigue effectively, they are able to return to the activities they may miss when their fatigue is untreated.

Many management techniques have been suggested for fatigue. There are three main categories of fatigue management:

- Managing your activity
- Improving your general health and wellbeing
- Managing your sleep

On the following pages, we will discuss each of these in more detail.

Managing your activity

Fatigue affects how much activity (either physical or mental) you can do, and you may find that your capacity for work or play is reduced a lot. It can be tempting to “tough it out” and try to force yourself to work through your fatigue. This is an unhelpful approach, as overworking or stressing yourself can not only trigger your symptoms in the short term, but has also been shown to make fatigue last longer with worse symptoms in the long run.

This means that the most important tool in managing your fatigue is to manage your activity. What you do, how much you do, and when you do it can all have big impacts on your health.

The first step in managing your activity is to understand the patterns of your symptoms. Keep a symptoms diary for 1-2 weeks to find these patterns. Then you can start to adjust your activities to avoid your fatigue triggers.



Rather than doing a lot all at once, which can make your symptoms worse, spread out activities and make time to rest.



Plan and prioritise your work in advance. If you can, break work up into smaller tasks.



Try to make time for things you enjoy. If you're too tired to do a fun activity, though, remember it's okay to back out of it!



If your symptoms are worse at a certain time of day, plan your routine around this.



Know your limits, and increase them gradually. If your symptoms get worse, reduce your activity level.



Try to balance mental and physical activities.

Improving your health and wellbeing

Your fatigue is closely linked to your overall health and wellbeing. This means that good lifestyle changes, or management of any other health problems, can greatly improve your fatigue symptoms.

Any lifestyle changes you make, though, should take your fatigue into account. This is especially important with exercise. While physical exercise and fitness can be good in moderation, do not push yourself too hard. Overdoing it will worsen your fatigue, and is unsustainable and unhealthy.

If you think that there is a problem with your general health and wellbeing which may be affecting your fatigue, it is worth raising it with your doctor to discuss ways you can address your overall health without worsening your fatigue.



Smoking, drinking, and the use of drugs can all increase the strain on your body and worsen fatigue. If you need help quitting, speak to your doctor or pharmacist.



Try to maintain a regular routine.



Eat a healthy, balanced diet. Ensure that you eat regularly, even when you don't feel up to cooking – it can be helpful to have ready meals or healthy snacks on hand.



Immune-boosting supplements can help to rebalance your immune system.



Try to reduce stress and emotional upset where possible.



If you are working, speak to your manager about adjustments they can make to your schedule or tasks to accommodate your fatigue better.

Managing your sleep

Sleep quality is a big part of fatigue for many people. If you are suffering from fatigue, it is important to manage your sleep carefully.

It can be tempting to sleep for very long periods, but this will not necessarily make you less fatigued. Naps and long lie-ins can disturb your sleep further and prevent you from sleeping deeply at night. While you may need more sleep than you did before, it's best to stick to a regular routine for sleep, and to try and get as much of your sleep as possible in one uninterrupted stretch.

There are many techniques to improve the quality of your sleep. You may have heard these referred to as "sleep hygiene". The following page provides some information and advice on improving your sleep, but your doctor will probably be able to recommend other considerations if these don't help.



Try to go to bed at around the same time every night.



Relax and try to wind down before going to bed. Don't start new activities or projects in the evening if you can avoid it.



Avoid screens (phones, computers, etc.) for at least 30 minutes prior to sleeping.



Ensure your bedroom is quiet, dark, and a comfortable temperature.



A bedtime routine can help train your brain to recognise when it should sleep. This might mean having a hot drink, reading a book, listening to music, meditation or breathing exercises, or anything else you can repeat every night to help you get mentally ready for sleep.

Planning and prioritising

The most important thing you can do to manage your fatigue is to plan and prioritise your activity. This means taking a step back and accepting that you may not be able to do everything you want to.

Make sure that you make time for rest, and to do things that you enjoy.

Try to plan only one or two big, tiring tasks per day, at most.

Try to plan a balance of physical tasks and tasks that take emotional or mental effort.

It may help to use to-do lists, schedules, or diaries to visualise how much you have to do in a given day. If it looks like too much, think about what is less urgent or less important, and leave it to another day.

Activity diaries

Tracking your activity allows you to find the patterns in your fatigue. It also helps you to be aware of your energy level, how much activity you're doing, and what you might be able to change. A simple way to track this is to keep an activity diary.

Write down all the mental activities you have done during the day, for example, talking on the phone or reading a book.

Write down all the physical activities you have done during the day, for example, going for a walk or making dinner.

For each activity, rate your fatigue level afterwards from 1 (not at all) to 10 (very high)

Add in other details about your day and your activities if you want – when you did activities, how long for, your mood, etc. More information can show up more patterns.

Energy mapping

Energy mapping is another way to track your activity. This method uses a system of colour-coding to help you see how your time is distributed. A worksheet for this is available on our website – chss.org.uk

Each hour in the day has a box on the sheet, which can be filled in with the appropriate colour. You can then see at a glance how much time you spend in different levels of activity, and when. This can also help you to set limits for yourself, and to monitor how well you keep to them.

Set limits by looking at your energy maps for the previous week or two to see how many hours coloured in red (high-energy activity) you can maintain daily for at least three days without your symptoms worsening. You should aim to set these time limits low, rather than high. Review them every month or two.

RED is high-energy activity. This is anything which feels, to you, like an active expenditure of energy. This will always include things like exercise, work, or studying, but depending on how severe your fatigue is, it may also include smaller tasks like showering, simple housework, or intense conversations.

YELLOW is medium-energy activity. This is any activity which requires some active engagement, but which you don't expect to be consciously tiring. For most people, this will include things like watching television without being deeply engaged, chatting to friends, or reading short, simple documents.

GREEN is rest. This is time in which you are awake, but not taking part in any activity.

BLUE is sleep. Tracking this will also help with the sleep management techniques we discussed earlier.

Keeping active

Regular exercise can help to maintain your schedule, support your overall wellbeing and fitness, and boost your immune system. However, it is crucial that you do not over-exercise. Balance is key!



Remember that daily tasks like housework or walking around the house are still exercise.



Don't feel guilty for not doing "enough". Any exercise is enough, even if all you can do is sit up in bed.



If exercise makes you fatigued or is painful, listen to your body and stop or slow down as needed.



Try gentle exercises like pilates, yoga, or swimming, rather than high-impact exercises that get your heart rate up.

Preparing for flare-ups

It's impossible to predict everything that may trigger your symptoms. If your symptoms flare up unexpectedly, it is helpful to be prepared, particularly if you live alone.

Have ready-made or easy-to-cook food in stock, for days when cooking is more than you can manage.

If you live alone, you may also want to keep some high-energy snacks nearby, in case you can't get to the kitchen.

Keep a glass of water and any medication you may need within reach of your bed.

If you live alone, ask a friend or family member to call in regularly to check on you.

Discuss work leave arrangements in advance, if necessary.

Asking for help

It is important to have a support network around you while struggling with fatigue. This might include:

- Family and friends
- Your doctor
- Your work colleagues
- Your manager or boss (who is legally required to support you with reasonable work adjustments)
- Healthcare services
- Support groups and community networks
- The CHSS Advice Line (**0800 801 0899**)
- CHSS Hospital to Home services.

Remember: there's no shame in asking for help!



Finding support

While Long Covid is a new condition, there are many existing support resources for Chronic Fatigue Syndrome and connected conditions which can be very helpful for your fatigue management, and for finding people with similar experiences of fatigue symptoms.

The M.E. Association – meassociation.org.uk

Action for M.E. – actionforme.org.uk

U.K. Fibromyalgia – ukfibromyalgia.com

Chest Heart and Stroke Scotland is also developing a range of services and support for people with Long Covid, including support for fatigue. Check out chss.org.uk for more.



Our publications are available for free to anyone in Scotland who needs them. Go to www.chss.org.uk/publications for all our resources, including other Essential Guides in this series.

For free, confidential advice and support from our **Advice Line nurses**, call: 0808 801 0899 (Mon-Fri 9.30am-4pm), text: NURSE to 66777 or email: adviceline@chss.org.uk.

Across Scotland, over one million people – that's one in five of us – are living with the effects of a chest, heart or stroke condition. We are here to help everyone who needs us. But we need your support to do this. Go to www.chss.org.uk/supportus to find out how you can help more people in Scotland.

If you would like this resource in an alternative format, please contact our Advice Line nurses.

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