

Fatigue after stroke

Stroke Helpline: 0303 3033 100
or email: helpline@stroke.org.uk

Fatigue affects the majority of stroke survivors and it can have a big effect on your life. This guide looks at the causes and impact of fatigue, and suggests practical ways you can help yourself and seek support.

What is post-stroke fatigue?

Fatigue is different from normal tiredness, as it doesn't seem to get better with rest. It can happen after any type of stroke, big or small. It can also happen after a transient ischaemic attack (TIA, or mini-stroke).

The signs of fatigue vary between individuals, but you may feel like you lack energy or strength, and are constantly tired. It is not necessarily caused by being more active or working, so it is not like typical tiredness.

You might need to rest more than normal or want to sleep during the day. Fatigue could make it difficult for you to take part in everyday activities. It can also affect your recovery and rehabilitation.

If you think you have fatigue, it's a good idea to speak to your GP or therapist, as you may be able to get treatment for the cause of your fatigue. You can have help to understand the triggers for your fatigue, and how to manage it. Fatigue can get better over time, and you can help to improve your recovery by getting support and trying techniques for managing fatigue.

Who is affected by post-stroke fatigue?

People have different levels of fatigue, from mild to severe. It can happen after any type of stroke, and you can have severe fatigue after a relatively mild stroke or a TIA. Even if you have made a full physical recovery, or your stroke was some time ago, fatigue can still be a problem. Fatigue can start immediately after a stroke, and often improves over time, but it can also appear some time later.

Post-stroke fatigue may be more common among older people and women. It is not caused by depression and anxiety, although it's possible for someone with depression or low mood to also have post-stroke fatigue.

Many people describe fatigue as the most difficult and upsetting problem they have to cope with after a stroke. You may not feel able to engage fully in rehabilitation because you feel so tired. It can affect your ability to regain your independence in day-to-day life, and it can be difficult to return to work or to socialise and enjoy everyday activities.

It can also affect your quality of life and relationships, as family and friends may not understand how genuinely exhausted you feel on a daily basis.

Why do I feel so tired?

It is likely that a mixture of physical and emotional factors are contributing to you experiencing fatigue after stroke.

Physical causes

The physical impact of the stroke on your brain and body can trigger fatigue. In the early weeks and months after a stroke, your brain and body are healing. The rehabilitation process can involve trying to do things in a completely new way, or learning and doing exercises which can be very tiring.

You may have lost mobility and fitness while in hospital, or as a result of the stroke, and being physically inactive is linked to fatigue.

If you have muscle weakness after your stroke, this can mean you use energy in different ways. For example, walking and completing other daily activities may well take up much more energy than they did before your stroke, making you more likely to feel tired. However, even those who make a good physical recovery can still experience fatigue.

Emotional changes

Feeling depressed or anxious is common after a stroke, and can come with a sense of fatigue. If you feel your mood is low or you are feeling constantly irritable or tense then don't ignore it. Your GP can prescribe medication or refer you on for practical support such as counselling. See our guide 'A complete guide to emotional changes after stroke'.

Other factors

Other factors that can affect how tired you feel include sleeping problems such as insomnia and sleep apnoea (interrupted breathing). You might have trouble sleeping due to muscle stiffness or joint pain.

If you have trouble with swallowing or chewing, this could affect the amount of energy and nutrients you gain from your food.

Some health conditions such as anaemia (low levels of iron in the blood), diabetes or an underactive thyroid gland can also make you feel tired.

If you have pain after stroke such as muscle pain or headaches, this can also affect your energy levels.

Some common medications have fatigue as a side effect, such as beta blockers for high blood pressure, epilepsy drugs and antidepressants.

Managing your fatigue

Although there isn't a clearly defined treatment for post-stroke fatigue, there are some practical steps that you can take to reduce your fatigue.

It is important to get individual advice from a GP or other health professional, to ensure that you have identified any underlying health problems. They will also help you to get the right support with your fatigue.

Find out the cause of your fatigue

Try to find out if there are any treatable causes for your fatigue. Your GP or stroke nurse can check if you have any medical conditions that could be making you feel tired.

Ask the GP for a review of your current medication. If your fatigue is at least partly caused by side effects of your medication, it usually improves with time or once you start a new medication. Never stop taking your medication suddenly, and ask your GP for advice if you have any problems with side effects.

Help others understand your fatigue

Your tiredness may not be obvious to other people so they may not understand how you feel. This may be frustrating for you. Show your family and friends this guide to help them understand what you are going through. They can offer you support with your recovery and dealing with tasks.

Tips for reducing and managing fatigue

- Give yourself plenty of time. It can take many months before post-stroke fatigue starts to lift. Accepting that it takes time to improve can help you to cope better.
- Keep a written or visual diary of how much you are doing each day. Over time this really helps to remind you of the progress you've made and will help you understand how much activity you can cope with, and what triggers your fatigue. Don't push yourself to do too much if you're having a 'better day'. Although it is tempting, it may leave you exhausted for the next day or two.
- Celebrate your successes. Many people feel frustrated by what they can't do and forget to feel good about what they have started to do again.
- Learn to pace yourself by taking proper breaks before or after doing things. Even gentle activities like talking with friends, a car journey and eating a meal can be tiring.
- Rest and sleep: you might need to rest or nap during the day. But if you are having trouble sleeping at night, avoid sleeping during the day. Look for other ways to sleep better such as comfortable bedding and cotton sheets.
- Don't make it hard for yourself by trying to do all the things you used to do, or at the same speed. It can be helpful to lower your expectations of what you can achieve for a while, so you can build up stamina and strength again slowly.

- Find out how much you can do in a day and stick to it. For example, if you can achieve about four hours of activity a day (with rests in between) without being too tired then that is the right level for you. If you do too much, you will probably soon realise as you will need to rest more or have to spend a day in bed to recover.
- Build up stamina and strength slowly or you may well feel you are going backwards if your fatigue worsens. Increase your activity gradually. For ideas and advice see our guide 'Getting active after a stroke'.
- Start to wind down during the evening and get into a bedtime routine.
- Try to do some exercise, as this may help to improve fatigue. Start gently, for example a very short walk or a few minutes on an exercise bike, and slowly build up without overdoing it. Ask a physiotherapist for help with this.
- Eat healthily. Carbohydrates such as bread and pasta are good sources of energy, and try to eat at least five portions of fruit and vegetables each day. If you have trouble swallowing or eating after a stroke, you will need support from a dietician to help you eat the right types of food. Ask your GP to refer you for help.
- Seek support. Your GP or occupational therapist can help put you in touch with different types of support, for example stroke clubs, counselling, relaxation programmes, exercise groups or alternative therapies. Contact us for details of stroke clubs and other support in your area (see Where to get help and information).

Work and fatigue

If you are working, or thinking of going back to work, fatigue can have an impact on you. These practical tips may help, as well as seeking professional support and advice.

- Your workplace could be assessed by an occupational therapist. They will advise whether to adapt any equipment you use or change work practices. If you don't have an occupational therapist, your GP can refer you, or your employer may appoint one.
- Give yourself plenty of time to recover from your stroke before going back to work. Putting pressure on yourself could make it harder.
- Talk to your employer about your stroke and how it has affected you. This can help them to make any reasonable adjustments needed to help you to do your job such as having more frequent breaks.
- You could talk to your colleagues and explain your post-stroke fatigue. Because the tiredness is not visible it is unlikely they will know about it unless you tell them.
- Think about having a phased return. This could mean returning to work part-time to start with, sometimes only for a couple of hours each day or every other day. Some people find that fatigue occurs later in the day and feels like 'hitting a wall'. To help you manage your energy levels, you can start with tasks and working hours that are manageable for you and build up slowly. Talk to your employer and agree a plan that works for both of you.

For information about work, stroke and your legal rights, see our guide 'A complete guide to work and stroke'.

Where to get help and information

From the Stroke Association

Helpline

Our Helpline offers information and support for anyone affected by stroke, including family, friends and carers.

Call us on **0303 3033 100**, from a textphone **18001 0303 3033 100**
Email helpline@stroke.org.uk.

Read our information

Get more information about stroke online at stroke.org.uk, or call the Helpline to ask for printed copies of our guides.

My Stroke Guide

The Stroke Association's online tool My Stroke Guide gives you free access to trusted advice, information and support 24/7. My Stroke Guide connects you to our online community, to find out how others manage their recovery.

Log on to mystrokeguide.com today.

Other sources of help and information

Headway

Website: headway.org.uk

Tel: **0808 800 2244**

A brain injury charity with information and advice including the 'Managing fatigue after brain injury' guide.

NHS Choices

Website:

nhs.uk/Livewell/tiredness-and-fatigue

Provides general information about tiredness and fatigue, including sleeping advice and tips on combating fatigue.

Royal College of Occupational Therapists (RCOT)

Website: rcot.co.uk

Tel: **020 3141 4600**

The RCOT is the professional body for occupational therapists in the UK. It has a number of specialist sections covering areas like neurological practice and independent (private) practice and offers a list of private therapists and advice on choosing an occupational therapist.

About our information

We want to provide the best information for people affected by stroke. That's why we ask stroke survivors and their families, as well as medical experts, to help us put our publications together.

How did we do?

To tell us what you think of this guide, or to request a list of the sources we used to create it, email us at feedback@stroke.org.uk.

Accessible formats

Visit our website if you need this information in audio, large print or braille.

Always get individual advice

This guide contains general information about stroke. But if you have a problem, you should get individual advice from a professional such as a GP or pharmacist. Our Helpline can also help you find support. We work very hard to give you the latest facts, but some things change. We don't control the information provided by other organisations or websites.

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Every five minutes, stroke destroys lives. We need your support to help rebuild them. Donate or find out more at stroke.org.uk.

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