

A decorative graphic consisting of a solid green horizontal bar at the top, followed by a large blue area with the title text. Below the blue area is a wavy, layered graphic with a light green top layer and a dark blue bottom layer.

Fatigue after stroke

What is post-stroke fatigue?

Tiredness affects everyone, and there are many reasons why you might feel tired, such as lack of sleep or a busy day. Usually a good rest makes you feel better.

Post-stroke fatigue can be characterised by a lack of energy, or the need to rest every day or nearly every day. If this has occurred since your stroke, or over a period of two weeks within the last month, it is likely that you are suffering from post-stroke fatigue. Both severe and mild strokes may cause post-stroke fatigue.

Post-stroke fatigue is very variable, and whilst some people have relatively mild symptoms, others may experience severe fatigue, leading to significant limitations in their ability to carry out day to day activities.

For many people, fatigue is the most difficult problem they have to manage with after stroke. It can be frustrating and upsetting as it is not necessarily visible to friends, family and colleagues. It may also lead to you not being able to engage as fully in rehabilitation, and other everyday activities such as work and socialising. It can therefore also affect your quality of life and relationships.

It is really important to let people know about your fatigue, in order to help others understand what you are going through. It is also important to let the team looking after you know. We may be able to alter your treatment accordingly, and help to provide the best opportunity to recover.

What causes post-stroke fatigue?

It is not entirely clear what causes post-stroke fatigue, and why some people are more affected than others.

The relationship between fatigue and age, gender, health prior to stroke and employment is not clear, and therefore predicting how much you

will be affected by fatigue and how long it will last may not be possible. After a stroke, physical and mental activities may require more effort, contributing to fatigue. Other contributory factors may include pain, poor sleep and breathing problems. Pre-existing medical conditions (such as heart disease, or arthritis) may also play a role, as can certain medications (some of which may be prescribed after stroke). Nutritional deficiencies can also contribute to fatigue.

What triggers fatigue?

Triggers for fatigue can be different for everyone. The things that trigger post stroke fatigue may also be very different from what you have experienced prior to your stroke.

Some activities, which are physically strenuous, may trigger fatigue:-

- Going for a walk
- Going to the gym
- Doing the house work
- Playing with the children/grandchildren.

Less obvious triggers for fatigue are activities which use cognitive (thinking) or emotional energy. Especially tasks where you need to sustain your attention, or process a lot of information. These activities might seem quite passive from a physical point of view, however, they make your brain work hard!

- Working at the computer
- Reading a book
- Watching television
- Being in a busy environment
- Dealing with a dispute.

It is useful to learn what your own triggers are, and this will take time to identify. Look at the list in the next section 'How might you feel', to help you identify when you might be experiencing fatigue.

How might you feel?

Post stroke fatigue is described as ‘an overwhelming sense of tiredness, exhaustion, lack of energy, or difficulties with sustaining routine actions’, and it may come on suddenly. It is abnormal or excessive to ‘normal’ fatigue, and can interfere with participation of daily activities (*Flinn and Stube, 2009*).

People may feel **physically, cognitively** or **psychologically** fatigued, and this may effect physical, cognitive, psychological and behavioural abilities. For example:

Physically

- Feeling like the you have flu
- Needing to take naps in the day

Cognitively

- Difficulties concentrating for long periods
- ‘Feeling less sociable, unable to tolerate crowds and busy environments

Psychologically

- Frustration at being unable to do as much as before
- Concerned about families understanding. Do they think I am being lazy?

Any, or a combination of the above, can lead to **behavioural changes**. For example – feeling irritable, becoming less sociable, having reduced levels of activity, and being more dependent on family. However, there are strategies you can use to reduce this (See the section ‘how can you manage Fatigue?’).

How common is post-stroke fatigue?

You are most likely to experience fatigue shortly after your stroke.

The severity of post-stroke fatigue does not seem to be related to the severity or type of stroke you have had. Furthermore, post-stroke fatigue is as common amongst those who have had a stroke caused by a bleed from a blood vessel supplying part of the brain (haemorrhagic stroke) as with those whose stroke has been caused by a blockage of a blood vessel supplying part of the brain (ischaemic stroke).

You are more likely to experience fatigue after a stroke than after a transient ischaemic attack (TIA), sometimes called a mini stroke.

Fatigue can continue to be a problem for a while after your stroke, and even if you have made a full physical recovery.

How can you manage fatigue?

What is making you tired. Make a list, or keep a diary. Is it certain activities, certain times of the day, or being in a particular environment?

What are your priorities. Identify the things you need to do, and that you want to do the most. Things that you don't have to do, or don't particularly want to do can wait/be left or be done by someone else!

Break tasks down. If you want to cook a roast dinner on a Sunday, but find it very tiring, can you break the task down? Prepare some veg the night before, or in the morning, and then have a rest.

Adapt the activity. Can you reduce the energy (cognitive or physical) needed for the activity? For example, sitting down to shower or wash rather than standing, or listening to an audio book, if reading makes you tired.

Get proper rest. Reading, watching TV or having a chat can all sound like restful activities, but if you have post stroke fatigue, they may not be!

Pacing. It is a good idea to pace yourself, or you may find you have one good day, followed by a day when you are completely exhausted. Trial and error will help you know how much you can do in one go. Once you do know, make sure you take a break when needed.

Planning and organising. If you have activities that you want to do over the course of a week, plan and organise how you are going to manage your fatigue. For example, if you want to go swimming, have a meal out with the family, and go to the shops, leave a day in between which will be more restful. Use a timetable if this helps you to plan.

Are there any treatments for post-stroke fatigue?

The first step to managing fatigue is getting a proper diagnosis. Therefore, if you are experiencing symptoms that you think may be post-stroke fatigue, speak to your doctor, stroke nurse or one of the therapists.

There is no specific medication to treat post-stroke fatigue. However, it is possible that other medical conditions could be affecting your fatigue, some of which may be diagnosed after a consultation and/or blood test, and can be treated. This is something that your doctor or stroke nurse can check for.

It is also worthwhile reviewing your current medication with your doctor. Occasionally fatigue can be partly contributed to by medication side effects, and in these circumstances a change in prescription may be considered. This may result in a gradual improvement in symptoms. However, you should not suddenly stop taking your medication, as these changes may need to be done gradually. Seek advice from your GP or stroke specialist.

What about work?

Most people want to return to work if they can. The following information may help to give you the best chance of doing so successfully.

An occupational therapist can assess your workplace, and advise if you may need adjustments at work, including changes to your work hours or practices. They will also advise if there is equipment that might help to support you. Referral to an occupational therapist can be done by the team looking after you in hospital, your GP, or your specialist stroke nurse or doctor.

It is important that your employer and colleagues are aware of your post-stroke fatigue and how it may affect your work. If you are concerned that they will not understand, then bring a medical report.

If you are working with an Occupational Therapist, they may suggest that they meet your employer with you.

Before you return to work give yourself plenty of time to recover. If you try to do too much too early this will only make it more difficult.

Often a graded return to work may be advisable. You may decide to work part-time to begin with, a few hours per day, or alternate days, and build this up over a few weeks. Speak to your employer about options and what is best for you.

Getting back to work is not always possible. You may need to work fewer hours, or consider changing jobs if the fatigue means that you are unable to manage your old job. You may even need to stop working, and this may be difficult to accept. Please see information below for contact details of support groups.

Useful contacts

Stroke Association

National helpline: 0303 303 3100

<https://www.stroke.org.uk/>

Different strokes

0345 130 1712

<http://differentstrokes.co.uk/>

Headway East Sussex

01825 724323

<http://www.headwayeastsussex.org.uk/>

Stroke Support Uk (East Sussex groups)

07999 962208

<http://www.strokesupport-uk.com/contact.html>

Croydon Stroke support group

01444 458075 0795 256 5285

esther.hickman7@gmail.com

<https://www.croydonstrokesupport.co.uk/>

Four Deans Stroke Club,

Woodingdean

David Hunt 01273 303236

Friends of Hove Stroke Club

Mrs Nina Shaw

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Ref number: 843

Publication Date: November 2017 Review Date: November 2019



carer and patient information group approved