

Fatigue after stroke

Fatigue is one of the most common effects of stroke. It can make you feel unwell and like you're not in control of your recovery. The signs of fatigue are not always obvious to other people and so they may not understand how you are feeling. This factsheet explains what fatigue is, what can cause fatigue after stroke and suggests ways you can help yourself and seek support in the longer term.

What is post-stroke fatigue?

Everyone feels tired sometimes. It is a normal part of life and can happen for all sorts of reasons, such as if you haven't slept well or have had a very busy day. Usually you feel better after resting.

Fatigue after stroke is different. After a stroke, you may feel like you lack energy or strength and feel constantly weary or tired. Post-stroke fatigue does not always improve with rest and is not necessarily related to recent activity. So it is **not like typical tiredness**. You might experience post-stroke fatigue after a mild or more severe stroke.

Here are some **useful definitions** of fatigue after stroke. If either of these apply to you, you may have post-stroke fatigue:

1. Over the past month there has been a period of at least two weeks when you have experienced fatigue, a lack of energy or increased need to rest every day or nearly every day. This fatigue makes it difficult for you to take part in everyday activities.

2. Since your stroke you have experienced fatigue, lack of energy or increased need to rest every day or nearly every day. This fatigue makes it difficult for you to take part in everyday activities. (If you are in hospital this may include taking part in a therapy session or having to stop a session early because you are tired.)

You might be tempted to dismiss how you are feeling or stoically carry on regardless. However if you do ignore fatigue, you could be storing up problems for the future and you are not giving yourself the best opportunity to recover.

How common is post-stroke fatigue?

There have been a number of research studies on fatigue after stroke. In one study, two years after their stroke 10 per cent of stroke survivors said they were always tired and 30 per cent said they were sometimes tired. In another study, at least 12 months after their stroke, **50 per cent of stroke survivors said tiredness was their main problem**. You are most likely to experience fatigue shortly after your stroke.

Post-stroke fatigue can range from relatively mild to severe and the **intensity of the tiredness does not seem to be related to the severity or type of stroke you have had**. Post-stroke fatigue is just as common after strokes caused by bleeding in the brain (haemorrhagic strokes) as those due to a blockage in a blood vessel (ischaemic strokes). We do know that you are more likely to experience fatigue after a stroke than after a transient ischaemic attack (TIA), sometimes called a mini stroke.

Even if you have made a full physical recovery, or your stroke was some time ago, fatigue can still be a constant problem.

Some research studies show that women, older people and those who suffered from fatigue before their stroke are the ones most likely to experience it. However, other studies show younger people and those who were previously completely fit can also feel tired after a stroke. Other individual studies made a connection between being unemployed and having fatigue after stroke. But the relationship is not clear and more research is needed.

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 again and enjoy everyday activities.

It can also affect your quality of life and relationships, as family and friends may not understand how genuinely exhausting the fatigue can be.

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, even though we don't fully know what makes some people have fatigue when others do not. The main reason for you being tired is simply that you have had a stroke.

How you might feel in the early stages

In the early weeks and months after a stroke your body is healing and the rehabilitation process takes up a lot of energy so it is very common to feel tired.

You are also more likely to have lost strength and fitness whilst being in hospital or as a result of the stroke, although this does not always mean you will have post-stroke fatigue.

How you might feel later on

In the long term, having a physical disability also means your energy is being used 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.

Emotional changes

Feeling depressed and/or anxious is common after a stroke. Many people who suffer from fatigue after stroke, also feel depressed or anxious. However, although most people with depression do feel tired, not everyone with fatigue is depressed. 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

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and/or refer you on for support and advice such as counselling. See our factsheets *F10, Depression after stroke* and *F36, Emotional changes after stroke* for more information.

Other factors

Other factors that can affect how tired you feel include sleeping problems such as insomnia and sleep-related breathing disorders (such as sleep apnoea); eating problems; anaemia (iron deficiency); diabetes or an underactive thyroid gland.

Some **medication** also causes fatigue. For example, beta blockers for high blood pressure, drugs for epilepsy, pain and anti-depressants can all cause fatigue.

It has also been suggested that fatigue may be associated with inflammatory cells or hormones (such as cortisol) that are disturbed by the stroke.

What treatment is available?

There is **no specific medication** to treat post-stroke fatigue. However, there are a lot of things you can do to manage the condition.

Getting a proper **diagnosis** and finding out if there are any specific causes for your fatigue is the first step.

Your **GP** or **stroke nurse** can check if there are any medical conditions that could be affecting your fatigue. Some can be picked up with a blood test and can be treated.

Reviewing your current medication is also worthwhile. 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** because you think it is making you tired – some medication has to be stopped gradually. Talk to your **GP** or **stroke specialist** for advice.

Managing your fatigue

Below are some suggestions to help you manage your fatigue. These include tips to help you with any emotional problems (for example frustration, loss of control and worry) as well as practical problems (less activity, reduced social life, impact on work and disturbed sleeping pattern).

- Being tired is very common after a stroke. It can happen to anyone, so remember it is not your fault.
- 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 factsheet to help them understand what you are going through. They can then help you deal with it.
- Give yourself plenty of time. It can take many months before post-stroke fatigue starts to lift. The more you push yourself the worse you are likely to feel. 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.
- 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.
- Listen to your body. If you are exhausted during the day then rest. This could either be sitting or lying down or sleeping. There is no rule about how much time to rest for. However, if you are not sleeping at night then try resting less during the day.
- Don't make it hard for yourself by trying to do all the things you used to, 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, so increase your activity gradually.
- Start to wind down during the evening and get into a bedtime routine.
- Try to maintain some level of exercise, as regular exercise 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.
- 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 are not eating enough then ask your GP to refer you to a dietitian. See our factsheet *F8, Healthy Eating and stroke* for more information.
- Seek support. Fatigue can be very worrying and upsetting and just knowing it is because of the stroke can help. Your local stroke team, 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.

Can I go back to work?

Most people want to return to work if they can. Here are some pointers for giving you the best possible chance of doing this successfully.

- Your workplace could be assessed by an occupational therapist. They will look at whether it's necessary to adapt any equipment you use or change work practices. If you are not currently seeing an occupational therapist, your GP can refer you to one.
- Give yourself plenty of time to recover from your stroke before going back to work. Putting pressure on yourself will

only make it harder.

- It is very important to talk to your employer/colleagues and explain your post-stroke fatigue before you go back. Because the tiredness is not visible it is unlikely they will know about it unless you tell them. Take a medical report if you have one.
- Many people need to return to work part-time to start with, sometimes only for a couple of hours each day or every other day. Usually building up your time gradually over a few weeks is more effective than doing it quickly. Talk to your employer about what is best for you.
- Make sure you don't overload yourself when you first go back. The first few months are as much about looking after yourself as about work.

See our factsheet *F9, Stroke in younger adults* for more information about returning to work.

Getting back to work can be very satisfying, but it is not always possible. If the fatigue means you cannot return to your old job then you may have to look at working fewer hours or changing jobs. It may even mean you have to stop working. Accepting this may not be easy. Get as much support as you can. Contact us for details of support groups in your area.

Useful organisations

Stroke Association

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

Contact us for information about stroke, emotional support and details of local services and support groups.

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For sources used, visit stroke.org.uk

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