

Fatigue after brain injury



the brain injury association

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Fatigue is often described as a feeling of overwhelming tiredness, exhaustion, lacking in energy, weakness, being unable to motivate oneself, or sleepy. It is one of the most common effects of brain injury.

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People directly affected by brain injury can receive limited free copies of Headway print booklets by contacting the helpline on 0808 800 2244.

*print copy may contain minor differences due to revision of content



Introduction

This publication has been written for people who have had a brain injury and are experiencing fatigue. The information aims to help you, your family and friends to understand fatigue and how it affects you. Managing fatigue is not about taking it away but taking control of it. We hope that after reading the publication you will have discovered some new ways of managing your fatigue so that you can feel more in control and have more choice about what you do.

The information in this publication does not replace clinical guidance from medical professionals.

What is fatigue?

Fatigue is experienced by everyone at some point after a period of physical or mental activity and is a signal from our bodies telling us to take a break. 'Normal' fatigue is time-limited and alleviated by rest, whereas 'pathological' fatigue, such as that experienced following a brain injury, may be present most of the time. It may not immediately improve with rest and can affect a person's ability to be able to complete the activities they want to do.

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People describe three types of fatigue: physical, mental and emotional. These types of fatigue can interact with each other and may require different ways of managing their impact.

Fatigue after brain injury

Fatigue is a personal experience that is different for everyone. For some it may feel like overwhelming tiredness, which makes them unable to complete normal activities of daily living. People may say they feel exhausted, lacking in energy, weak, unable to motivate themselves, or sleepy. For others, it may worsen difficulties associated with their injury, for example forgetfulness, irritability, slurred speech, distractibility or dizziness.

Fatigue often makes resuming previous roles and daily activities more difficult and can contribute to people becoming socially isolated.

Therefore, fatigue may affect:

- What we think (e.g. “I shouldn’t feel like this, I’m useless”)
- How we feel (e.g. frustrated, unable to cope, irritable)
- What we do (e.g. avoiding activities, or increasing effort)

What causes fatigue after brain injury?

Many people experience fatigue following brain injury, but the underlying causes are still poorly understood. Fatigue may be a result of direct damage to brain structures, hormonal imbalances or due to other factors such as needing to make more effort and therefore use more energy to think or move.

The part of the brain that appears to be linked to fatigue is that which maintains alertness. This is known as the ascending reticular activating system (ARAS), and it links the brainstem with the thalamus, hypothalamus and cerebral cortex. The ARAS affects alertness by influencing the amount of information that the thalamus relays to conscious awareness.

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Research studies have shown that there are many different factors that make people vulnerable to experiencing fatigue and can affect how they respond to it.

Some of factors involved include:

- Anxiety and depression
- Sleep difficulties
- Medication side effects
- Reduced stamina
- Pain
- Hormonal changes
- Poor diet
- Individual ways of coping
- Knowledge of brain injury and its consequences
- Adjustment to changes in life
- Environment
- Social roles
- Other medical conditions
- Cognitive (thinking, information processing and learning) difficulties

Some of these factors may be managed more effectively to enable you to cope better with everyday activities that are important to you.

Tips for coping with some of these issues are offered in Headway's publications, available at www.headway.org.uk/information-

Recognising fatigue

In order to cope with fatigue you must first be able to recognise it. So how do you know when you are getting fatigued or fatigue is starting to build up?

Some signs may include:

- Yawning
- Losing concentration
- Eyes feeling heavy, or eyesight blurring

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you can plan for them in your daily routine. Once you are aware of which activities are more or less tiring, then you can prioritise and set yourself realistic targets of what is achievable in a day.

Managing your fatigue

For some people, fatigue improves over time. However, for many people fatigue is a condition that they have to learn to manage in the long-term.

There is no single cure for fatigue following brain injury, although recent research has found that cognitive behavioural therapy can help with managing fatigue by increasing a person's understanding of their experience of fatigue, triggers and ability to respond.

Managing fatigue requires a variety of strategies to address the factors that are contributing to it. Some of these strategies may seem like common sense and some you may already be applying. Taking the time to consistently put some of these principles into practice will hopefully allow you to cope better with everyday activities and feel more in control of your life.

The following information will address some of the factors that may be contributing to your fatigue and give you some ideas to try.

Mood-related factors

Fatigue is one of the main criteria used when diagnosing depression. However, not everyone who experiences fatigue is depressed. Brain injury can have a significant impact on mood and behaviour. This may be a consequence of direct damage to the brain itself or because of the impact the injury has had on an individual's life. Feeling depressed, stressed and anxious can leave you feeling tired. Equally, when people experience high levels of fatigue, which stops them from doing what they want to do, they may report feeling low and irritable.

Before triggers are identified, many people feel fatigue is something they are unable to control and this can lead them to feel helpless or hopeless. Typical coping strategies involve either trying to push oneself harder, therefore getting

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into a 'boom-bust' cycle of doing too much and then collapsing with tiredness, or avoiding certain activities altogether. However, as you learn more about what triggers your fatigue you can begin to identify ways of coping with it. By considering mood-related factors, levels of fatigue may also improve.

What can you do?

- Be realistic in your planning - pacing activities to avoid the boom-bust cycle
- If you don't complete an activity, try to reschedule it for when you are not fatigued
- Try not to dwell on things you haven't achieved. Notice when you have done things well and celebrate these achievements.
- Be aware of and acknowledge your feelings and emotions, but try not to dwell on them
- Plan time in your schedule to do pleasurable activities that will make you feel good about yourself
- Acknowledge that you may not be able to do as much as you did previously
- If you are really struggling with your mood, see your GP. Options may include medication, counselling or psychotherapy such as cognitive behavioural therapy (CBT).

Pacing

Pacing is a way of balancing activities that you do throughout the week. By spreading tasks out you may be able to reduce fatigue.

Pacing includes:

- Having regular rest breaks
- Planning your time and being organised
- Prioritising where to use your energy

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- Knowing what your triggers are and working within your available resources

It is important to plan when to take rest breaks during the day. Physically resting may require going somewhere quiet and sitting or lying down for a short period. It is better to take breaks often rather than having one long break when fatigue hits you. Engaging in relaxation can help you to cope with stress and can promote long-term health by slowing down the body and quieting the mind. Relaxation can also help improve energy levels, leaving you feeling refreshed and making you feel more mentally alert, thus making the most of your resources.

People with fatigue are advised to take regular breaks; however, some people find it hard to do nothing. Relaxation techniques can give a helpful focus and maximise the benefit of your rest periods.

'Power naps' have been found to be helpful; however, avoid sleeping for longer than 30 minutes during the day. Sleeping after 4pm may disrupt your sleep/wake cycle, so, if you need to take a nap, try to do this earlier in the day.

Prioritising involves thinking about all the activities you have to do each day/week and considering the following:

- Which jobs are most important or essential?
- Which activities do you enjoy?
- Which tasks could you delegate to someone else?
- Could you do any activities less often or eliminate them altogether?

Planning your time and being organised is vital to ensure that you achieve the tasks you set out to do. Plan your days around the times when you are at your best and the times when you are most fatigued.

Sleep hygiene

Sleep hygiene has nothing to do with personal hygiene, but is simply about having a regular sleep routine. This helps the body to prepare for going to sleep by winding down and helps you to feel more alert on waking.

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Things to try for sleep hygiene

- Establish a regular routine by going to bed at the same time each day, and getting up at the same time
- Use your bed for sleeping only - don't watch TV in bed
- Develop sleep rituals before going to bed to wind down and relax; for example, have a bath or listen to gentle music
- Get regular exposure to outdoors and bright lights during the day
- Avoid eating heavy meals late in the evening
- Reduce your intake of caffeine and nicotine in the hours before going to bed
- Avoid drinking alcohol for a few hours before going to bed
- Create a calm bedroom that is cool, dark and quiet - earplugs and blackout blinds can help
- Use relaxation techniques
- Avoid stress and worry at bedtime
- Avoid taking naps after 4pm

Try not to...

- Exercise within three hours of going to bed
Look at the time if you wake up, as this may make it difficult to get back to sleep
- Take another person's medication
- Have too much tea, chocolate, coffee or fizzy drinks in the evening

Some people may experience excessive daytime sleepiness or difficulty sleeping through the night following damage to specific areas of the brain. If these symptoms continue, discuss them with your GP. A referral to a sleep clinic for further assessment may be helpful in some cases.

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Exercise

Exercising improves our capacity to undertake physical activities. Current government guidelines recommend 150 minutes of moderately intense exercise a week to improve our physical fitness. Try to choose something which you enjoy as you are more likely to stick to it.

Some people report that exercise has an energising effect and research shows that it can have a positive effect on mood. Exercise can also help you to sleep more deeply.

Ways to introduce exercise into your daily activities:

- Park the car further away from work, or at the other side of the supermarket car park
- Get off the bus a stop before your destination
- Take the stairs instead of the lift or escalator

It is important to try and make exercise a habit by planning for it during your day and week. Before starting a new exercise regime, it would be helpful to discuss this with your GP and to find out if they offer a referral scheme with your local leisure centre.

Nutrition and hydration

Some types of food can make us feel more 'sluggish' and lacking in energy, while others can help to maintain energy levels for longer periods. Thinking about eating the right things at the right times, according to what you are doing, is important in managing fatigue.

Fast-releasing carbohydrates, in foods such as sweets, sugary cereals, white bread and sugary drinks, break down quickly and flood the blood with too much sugar. Surges in blood sugar levels may result in a short-term increase in energy, followed by decreased energy and concentration.

Slow-releasing carbohydrates, in foods like brown rice, wholegrain pasta, fruit and vegetables, are more 'complex' and contain fibre that helps to slow down the release of sugar and so maintain energy levels. It is important for the diet to have

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a balance of 'complex' carbohydrates and protein from foods such as meat, fish, dairy products and nuts.

Drinking enough fluid, particularly water, keeps the brain and body hydrated. This is important to help the brain and body work effectively. Drinking lots of caffeine, such as in tea, coffee and some fizzy drinks, may increase your alertness initially, but this is often short-lived.

More guidance on maintaining a healthy lifestyle is available at www.nhs.uk/live-well.

Medication

There is currently very little research into the effectiveness of medication for managing fatigue following brain injury, although some types of medication have been found to be helpful with other conditions where fatigue is a symptom.

Medication may be helpful in managing other factors associated with your injury, such as anti-depressants for low mood, but it may also influence the fatigue you experience. Some side effects may include drowsiness and could make you feel more tired during the day.

It is important to discuss these issues with your GP, who should be able to advise you on the benefits of medication and suggest any alternatives.

Environmental modification

To make best use of your available mental and physical abilities you may want to think about the environment in which you live and work. Being organised and avoiding distraction can help to minimise the physical and mental effort that is required to complete an activity.

Suggestions

- 'Energy conservation' techniques will be helpful if you experience 'physical fatigue'; for example, sliding instead of lifting items, using a laundry basket on wheels or having items used regularly within easy reach.
- Organise your workspace, such as your kitchen or office area, keeping it as

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uncluttered as possible. Keep things in the same place so that you don't waste energy searching. Try to have 'a place for everything and everything in its place'. Use good lighting in order to prevent eye strain

- Use labels/signs to help you to find things more easily
- Think about turning off the TV or music when you are trying to concentrate on a task
- Prevent interruptions from other people - for instance, put a 'Do Not Disturb' sign on the door.

Cognitive strategies

Following a brain injury you may need more mental effort to perform a task and you may experience difficulty sustaining this effort over time. Some people have described reaching a point at which their brain 'shuts off'. When experiencing 'mental fatigue' people describe being unable to think clearly and have difficulty concentrating.

It may be that cognitive difficulties resulting from your brain injury may be more noticeable when you get fatigued. Everyone tends to become forgetful and make more mistakes when they feel tired. Therefore, making best use of your thinking resources through applying strategies may be a way to make fewer mistakes and make things take less effort.

Some cognitive strategies that might be useful are:

- Using checklists to help you stay on track, such as a shopping list
- Scheduling your time using a diary, smartphone, Google calendar or Filofax
- Using alarms to prompt you to stay on task or take breaks; these can be set on fitness trackers or smart watches, and may be linked through Google calendar or apps
- Doing one thing at a time to help your concentration
- Using flow charts for planning and decision making
- Using written notes or 'Post-its' as reminders, rather than trying to 'hold

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something in mind'

- Using cue cards to act as reminders

For strategies to compensate for your specific cognitive difficulties a clinical psychologist or occupational therapist could help. You could speak to your GP about referral to these services. Your local Headway group or branch may also be able to help.

Mindfulness

This is a technique through which you practice becoming consciously aware of the present moment and taking time to focus on your own thoughts, feelings and the things around you.

Although it is often used to help with depression, anxiety and stress, there is some evidence to suggest that mindfulness can help people with managing their symptoms of fatigue after brain injury as well. For more information and tips on how to practice mindfulness, visit the NHS Choices website at www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness.

Summary

Fatigue is a common problem after brain injury. For some people it may decrease over time, while for others it is something they will need to learn to manage in the longer term. By reading this publication, we hope you have become more aware of some of the factors that may be affecting your fatigue. You may have begun to recognise your personal triggers and may be starting to make some changes to your lifestyle that could enable you to do the things you want to do.

While you may feel it is an effort to think about and implement these changes, over time they will become a more automatic part of your daily life. Although you may still experience fatigue, hopefully you will understand it, gain control of it and be able to participate in more activities more frequently.

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To help summarise what you have learned, write down the answers to the following statements:

The factors that make me vulnerable to fatigue are...

My triggers include...

When I get fatigued I feel...

I can manage my fatigue by...

Authors and acknowledgements

This publication has been written by Donna Malley, Occupational Therapy Clinical Specialist, and Jacqui Wheatcroft (née Cooper), Senior Occupational Therapist. They have extensive experience working with clients with acquired brain injury and have both undertaken postgraduate research studies into management of fatigue following acquired brain injury.

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