Headway
the brain injury association

Fatigue

after brain injury

This publication describes what fatigue is and how it can affect people after brain injury. It describes common triggers to fatigue after brain injury, and offers strategies for coping with fatigue. It also explains how to get professional support with this issue.

This publication is also available as a printed booklet, which can be purchased from our online shop.

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Contents

Introduction 1
What is fatigue?..... 2
Fatigue after brain injury 2
Recognising fatigue after brain injury 4
Triggers to fatigue after brain injury 5
Managing fatigue after brain injury 6
Professional support for fatigue after brain injury 15
Summary 16
Acknowledgements 16

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 what fatigue is, how it affects you, how you can manage your fatigue and where you can get professional support from.

Managing fatigue is not about preventing it from happening but taking control of it. We hope that after reading this publication, you will have found some new ways of managing your fatigue so that you can feel more in control and have more choice about what you do and how you feel.

The information in this publication does not replace clinical guidance from medical professionals. You should always get advice from your GP or other suitably qualified professional for help with managing the effects of brain injury.

What is fatigue?

Fatigue is described in many different ways, so there is no single definition of it. However, it is generally described as: an extreme tiredness and lack of energy, not relieved by sleep or rest.

People also describe feeling exhausted, lacking in energy, weak, unable to motivate themselves, unable to focus on tasks, or sleepy.

Fatigue can affect a person's ability to complete activities, work or socialise with others. For some, it occurs during or after certain activities, and for others it seems to be present most of the time.

Fatigue can affect people physically, mentally and emotionally.

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. This type of fatigue is time-limited and improved by rest. 'Pathological fatigue', which is found in several neurological conditions, including brain injury, may be present most of the time and not immediately improved with rest.

Fatigue after brain injury

Fatigue is one of the most common effects of brain injury. While fatigue may naturally improve over time, for many it can be a long-term challenge that requires coping strategies to manage effectively.

Fatigue can worsen other effects of brain injury, such as memory problems, irritability, slurred speech or dizziness. Conversely, coping with the impact of brain injury can affect energy levels, mood and sleeping habits, which can, in turn, worsen fatigue.

People often describe fatigue after brain injury as ‘fluctuating’. This means that it is not the same all of the time, but can worsen at different times of the day, or depending on activities completed. For example, people may experience worsened fatigue after a shopping trip, where they have to travel, get parked, follow a list and have a lot of light and noise to contend with. Others may find an evening out with friends exhausting, where they have to focus on communicating and eating.

Fatigue can make it difficult to return to former activities. For example, fatigue might make it difficult for someone to return to a previous job. Fatigue can also interfere with the ability to complete activities of daily living, such as washing, dressing or cooking. People may become socially isolated if they are unable to regularly join in with social activities due to fatigue.

What factors affect fatigue after brain injury?

There are many factors that can make people more vulnerable to fatigue and affect how they respond to it. This can include medication side effects, pain, poor diet, lack of knowledge of brain injury and the presence of other medical conditions. It might be possible to manage some of these factors to improve fatigue, such as improving your diet or learning about brain injury. Further information and suggestions are available in the section *Managing fatigue after brain injury*.

Reflection

In this section, we have explained the different ways in which people describe fatigue after brain injury. How would you describe your experience of fatigue? What words would you use to describe it, and how would you explain it to others?

Recognising fatigue after brain injury

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?

The most important thing that you can do is to learn to ‘tune in’ to your body. Fatigue is your body’s way of telling you to slow down and rest. Learning to spot the early signs of fatigue from your body can help with managing it effectively.

Some signs may include:

- yawning
- losing concentration/attention
- eyes feeling heavy, or eyesight blurring
- head feeling ‘fuzzy’
- fidgeting
- getting irritable
- limbs feeling heavy
- stomach feeling sick

You can also start trying to identify situations that cause you to feel fatigued. For example, if you begin to notice that travelling on the bus makes you feel fatigued, then next time you need to travel on a bus you can plan your day more carefully to minimise the impact of this.

It is important to understand that fatigue has to be managed. You can not push your way through it as this will likely make you feel worse.

Reflection

Think about the following: what signs does your body give you that you are starting to get fatigued? How does it feel, what do you think, and how do you react? It might be helpful to ask your family and friends what signs they notice, and to discuss this with you.

Triggers to fatigue after brain injury

A ‘trigger’ for fatigue is an activity, situation or stimulus (e.g. noise, lights, temperature) that typically causes fatigue to start.

Things that trigger fatigue will be different for everyone. Some examples of activities commonly reported to be triggers for fatigue after brain injury include the following:

- working at a computer;
- dealing with paperwork/correspondence;
- being in a busy environment such as a shopping centre;
- concentrating on one conversation in a noisy place like a pub;
- travelling and unstructured times e.g. weekends or holidays.

Reflection

It may take time to work out what your triggers are, so fatigue might feel difficult to control. However, it is likely that certain activities are more tiring for you; what are these? People around you may be able to help you to identify what these are.

You might want to consider monitoring your fatigue by rating how tired you feel before and after different activities, perhaps on a scale of 1 - 10. This may give you an idea of which activities you find more or less fatiguing. You may wish to consider doing this regularly by keeping a ‘fatigue diary’ to help you with spotting patterns.

It is important to recognise those activities or situations that are more tiring so that 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. For example, if you start to notice that

you regularly feel fatigued in the early afternoon, you can avoid booking appointments or social events at this time. Unfortunately, for some people there are no obvious triggers to feeling fatigue. They have to gradually learn to manage this when it arises.

Managing fatigue after brain injury

For some people fatigue improves naturally over time. However, for others, fatigue is a condition that they have to learn to manage.

There is no cure for fatigue following brain injury. However, there are strategies that might be able to help, by addressing the factors contributing to it.

This section offers information on some of the factors that may be contributing to your fatigue and offers suggestions of strategies to try and tackle them.

Some of these strategies may seem like common sense. However, taking the time to practice them regularly might help with forming good habits that may help you to cope better with your fatigue.

Mood

Brain injury can have a significant impact on mood, for instance causing feelings of anxiety, stress or depression. These changes in mood can contribute to feeling fatigued.

Conversely, being unable to complete regular activities because of fatigue may in turn lead to feelings of anxiety, stress or low mood/depression. Many people feel fatigue is something they are unable to control, and this can lead them to feeling helpless or hopeless.

People often get into a ‘boom-bust’ cycle of trying to push themselves through fatigue to complete activities, but then doing too much and collapsing with tiredness. Or they may avoid certain activities altogether from fear of getting fatigued. Both strategies are ineffective and can have a negative impact on mood.

As you learn more about what triggers your fatigue you may be able to begin to identify ways of coping with it. By considering mood-related factors, levels of fatigue may also improve.

What can you do?

- Keep in mind that fatigue is very common after brain injury. Learning about others’ experiences of fatigue after brain injury can help you to feel less isolated. Visit our website to find out how we can help you to connect with others affected by brain injury.

- Try not to dwell on things that you haven’t achieved. Instead, notice when you have done things well and celebrate these achievements. It is often helpful to break activities down into chunks - and then aim to achieve parts of these with resting e.g. getting washed and dressed can be broken down into sections with rest.

- Always plan time for activities that make you feel positive or good about yourself.

- Be patient with yourself as you learn to adjust to life after brain injury. Remember that brain injury can be a life-changing experience, but for many, things can and do get better over time.

- Talk to others about how you are feeling, and tell them about your fatigue, including any triggers. Others in your life may not know about brain injury or the long-term impact that it can have. They may not understand fatigue. Explaining how you feel might help others to be more accommodating to your changed circumstances. You can also be honest about needing time away from communication when feeling fatigued, and anything friends and family can do to help out.

- See your GP if you are struggling with your mood. Treatment options may include medication, counselling or psychotherapy. More information on this is available in the section *Professional support for fatigue after brain injury*.

- Refer to our publications *Depression after brain injury* and *Anxiety after brain injury* for more information on these topics and tips for coping.

Pacing

Pacing is a way of balancing activities that you do and spreading these out over time rather than trying to do too much in one go. This may be during a day or throughout a week - whatever works for you. By spreading tasks out you may be able to avoid getting overwhelmed and therefore reduce fatigue.

Pacing can include having regular breaks and resting, prioritising, and planning and being organised. We discuss each of these in further detail below.

Regular breaks and resting

It is important to take regular breaks, especially during busy periods. Resting may require going somewhere quiet and sitting or lying down for a short period of time. It is better to take

short breaks regularly, rather than having one long break when you are already feeling fatigued.

Some people find it hard to do nothing while taking breaks. Some find relaxation techniques, such as mindfulness or taking a warm bath/shower, can give a helpful focus.

Avoid using rest breaks for activities such as scrolling on your phone or watching TV, as these are actually quite cognitively demanding and may leave you feeling worse.

Relaxing while taking breaks can help to cope with stress and promote long-term health by slowing down the body and quieting the mind. Relaxation can also help to improve energy levels, leaving you feeling refreshed and more mentally alert. It can be especially beneficial, if possible, to spend some time outside in nature when resting.

'Power naps' have been found to be helpful. However, if you need to take a nap, try to do this earlier in the day, so that you do not disrupt your sleep/wake cycle. Set an alarm to manage this if you need to.

Prioritising

Prioritising involves thinking about the activities you have to do and considering the following:

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

Planning your time and being organised

Planning your time carefully and being organised is important

as it helps you to achieve tasks and undertake activities that you want to do without getting overwhelmed. If you are able to understand your fatigue triggers, you can plan activities carefully around this.

Some people have difficulties with planning and organising after brain injury. These skills form part of a skillset called executive function. When these skills are affected after brain injury, it is called executive dysfunction. More information on this and tips for coping are available in our publication *Executive dysfunction after brain injury*.

Sleep hygiene

Sleep hygiene is nothing to do with personal hygiene, but is simply a term used to describe having a regular 'good' sleep routine. Preparing the body for going to sleep by winding down is thought by some experts to help you to have a better sleep and to help you to feel more alert on waking.

Below are some suggestions for things to try and things to avoid for sleep hygiene.

Try to…

- establish a regular routine by going to bed at the same time each day, and getting up at the same time;
- develop sleep rituals before going to bed to wind down and relax, for example having a bath or shower, listening to gentle music or reading a book;
- have regular exposure to outdoors during the day;
- reduce your intake of caffeine, nicotine, and fizzy drinks in the hours before going to bed;

- create a calm bedroom that is cool, dark and quiet - earplugs and blackout blinds can help;
- consider trying out relaxation techniques, such as mindfulness and deep breathing.

Try not to…

- exercise within a few hours of going to bed;
- use your bed for watching TV or scrolling through your phone;
- eat heavy meals or drink alcohol a few hours before going to bed;
- take a nap late in the afternoon;
- do something that you know is likely to make you stressed or worried at bedtime.

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.

For further information on managing sleep after brain injury, see our publication *Sleep problems after brain injury*.

Exercise

Exercising improves our capacity to undertake physical activities. It can also positively affect mood, and help you to sleep more deeply, which may contribute to improving fatigue.

When choosing an exercise, try to choose something which you enjoy as you are more likely to stick to it. You should also

choose exercises that are safe for you. It may be necessary to consult your GP or a physiotherapist to check what you should or should not do.

Ways to introduce exercise into your everyday 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 to make exercise a habit by planning for it during your day and week. However, it is often counterproductive to exercise too late in the evening.

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 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 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 to 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.

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. If you believe a particular medication is contributing to your fatigue, you should discuss this with your GP or consultant.

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.

Below are some suggestions for modifying your environment to help with fatigue.

- ‘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 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'.

- 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 if you are resting.

Cognitive strategies

The term 'cognitive' refers to the mental processes involved in learning, remembering and processing information.

A brain injury can cause cognitive impairment, affecting skills such as memory, decision making, multitasking and concentration. More mental effort will be required to perform tasks that rely on these skills. Some people may have difficulties with sustaining this effort over time, thereby causing them to feel fatigued.

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.

Cognitive strategies that may help with fatigue include:

- using checklists to help you stay on track, such as a shopping list;
- scheduling your time using a diary, smartphone, calendar apps or Filofax;

- using alarms to prompt you to stay on task or take breaks;
- 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 something in mind’;
- using cue cards to act as reminders.

Professionals such as clinical neuropsychologists and occupational therapists might also be able to advise on specific strategies to help with specific cognitive difficulties.

Professional support for fatigue after brain injury

We hope that some of the strategies suggested in the previous chapter are helpful with managing fatigue. Unfortunately, in some cases people may still have difficulties with their fatigue, which may require support from an appropriate professional.

You should start by talking things through with your GP. They might be able to prescribe suitable medication, or refer you to a fatigue clinic (if locally available) or relevant professionals. For instance, clinical neuropsychologists can help with learning to cope with the psychological, cognitive, emotional or behavioural effects of brain injury that may be causing your fatigue. Occupational therapists might be able to suggest ways of adapting your environment or recommend useful adaptive equipment.

Talking therapies might be helpful. Recent research has found that a type of therapy called cognitive behavioural therapy can help with managing fatigue, by increasing a person’s understanding of fatigue, triggers, and ability to respond. If fatigue is being caused by problems with your mood, counselling might be a helpful option.

Summary

Fatigue is a common problem after brain injury. For some people it may improve over time, while for others it is something they will need to learn to manage in the longer term.

We hope that the information in this publication has helped you with understanding your fatigue and thinking about ways in which you can try to manage it.

While it might take effort to think about and introduce strategies to cope with fatigue, 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.

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

The factors that make me vulnerable to fatigue are…

Are there any triggers that bring on my fatigue? These are….

When I get fatigued I feel…

I can manage my fatigue by…

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We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2024.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

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