Managing fatigue after brain injury

Jacqui Wheatcroft, Donna Malley and Richard Morris

This booklet has been written for people who have had a brain injury and are experiencing fatigue. The information aims to help brain injury survivors, their families and friends to understand fatigue and how it affects them.
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Old Basford, Nottingham NG6 8SF

Authors: Jacqui Wheatcroft and Donna Malley

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Introduction

This booklet 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 your fatigue and how it affects you. Managing fatigue is not about taking it away but taking control of it. We hope that after reading this booklet 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 and how you feel.

What is fatigue?

Fatigue is experienced by everyone at some point after a period of physical or mental activity and is a signal telling us to take a break. ‘Normal’ fatigue is time-limited and alleviated by rest, whereas ‘pathological’ fatigue, such as that experienced following brain injury, may be present most of the time. It may not improve with rest and is likely to significantly impact on people being able to do the activities they want to do.
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 (for example, “I shouldn’t feel like this, I’m useless”)
- how we feel (for example, frustrated, unable to cope, irritable)
- what we do (for example, avoiding activities, or increasing effort)
Case studies

“It’s just like this cloud that comes over…my brain will shut off, it just can’t cope with it.”

“It’s almost like when I’m speaking to somebody I’m having to translate what they’re saying. It’s like they’re speaking in a foreign language…it takes so much effort to engage in conversation.”

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 or due to other factors such as needing to make more effort to think or move (see ‘Triggers to fatigue’).

The brain system that appears to be linked to fatigue is the part that maintains alertness. This is the ascending reticular activating system (ARAS), which links the brain stem with the thalamus, hypothalamus and cerebral cortex. The ARAS affects alertness by influencing the amount of sensory information that the thalamus relays to conscious awareness.
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 the factors involved include:**
- anxiety and depression
- sleep difficulties
- medication side effects
- reduced stamina
- pain
- physical difficulties
cognitive (thinking) difficulties
impaired sensation
hormonal changes
poor diet
individual ways of coping
knowledge of brain injury and its consequences
adjustment to changes in their lives
environment
social roles
other medical conditions.

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

Case studies
“Fatigue has stopped me doing many things which I have wanted to do. I feel miserable about this and more so for being tired. I get muddled about what it is I should be doing, how to do it and where, when I am tired.”

“I battle against it, as I am not a person who stops and relaxes and I don’t want to, even though I know I can cope better sometimes if I do. I still don’t want to give in trying to get on with everything I feel I should achieve.”
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/attention
- eyes feeling heavy, or eyesight blurring
- head feeling ‘fuzzy’
- fidgeting/getting irritable
- limbs feeling heavy
- stomach feeling sick

However, following brain injury it can be difficult to notice these signs. This may be due to problems with sensory feedback to the brain. What signs do you have that tell you that you are starting to get fatigued? How does it feel, what do you think and how do you behave? It may be helpful to ask your family and friends what signs they notice.

Case study

“Often it can creep up. It may not be so noticeable until you reach a crunch point where you become aware that… I just can’t deal with this anymore, or you can’t think straight.”
Things that trigger fatigue will be different for everyone. Some examples of activities reported to be more tiring following a brain injury include:
- 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
- driving or catching public transport

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.

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.
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. 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.

Case studies
“It is still a problem. Fatigue will always be an issue, but it is manageable with strategies.”

“Fatigue is something that can improve with a lifestyle change and awareness.”

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 stop 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 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 achieve an activity try to reschedule it for
  when you are not fatigued.
● Try not to brood 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).

Case studies
“I find it very difficult to cope with and I know I don’t usually actually help myself by trying to do too much.”

“I think acceptance, and also the fact that it is no shame to admit you are ‘shattered’, helps.”

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
• knowing what your triggers are and working within your available resources.

It is important to plan when to take rest breaks during the day. Resting requires 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 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, many people find it hard to do nothing. Relaxation techniques can give a helpful focus and maximise the benefit of your rest periods. To find out more about relaxation talk to your GP or health professional.

‘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 then 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 is 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.

Some dos and don’ts for sleep hygiene

**DO…**
- 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
- 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 a nap after 4pm
DON’T…

- 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.

Exercise

Exercising improves our capacity to undertake physical activities. Current government guidelines recommend 30 minutes of moderately intense exercise five times 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 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. 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 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.
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 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 – put a ‘Do Not Disturb’ sign on the door.

Cognitive (thinking) strategies

Following 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, electronic organiser, phone organiser 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

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 may also be able to help.

Mindfulness

This is a technique that entails being 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.
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 manage in the longer term. By reading this booklet, 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.

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

The factors that make me vulnerable to fatigue are ...
Managing fatigue after brain injury

My triggers include ...

When I get fatigued I feel ...

I can manage my fatigue by ...
Further reading

The following books are available from Headway and provide a good introduction to brain injury and its effects:


Headway's Amazon shop sells a wide range of books on the subject of brain injury and brain function.

Headway also produces an extensive range of booklets and factsheets covering the problems that brain injury can cause.
Managing fatigue after brain injury

To obtain a complete publications list or to order copies of books and booklets, please visit our website at https://shop.headway.org.uk/, or telephone 0115 924 0800.

Factsheets and e-booklets are free to download at www.headway.org.uk/information-library.

Brain injury survivors and carers can receive free print copies of appropriate booklets from the helpline on 0808 800 2244, or helpline@headway.org.uk.

The following books and internet resources provide further information on coping with fatigue:

- Coping with Fatigue – information section on the Macmillan Cancer Support website at www.macmillan.org.uk (see ‘Useful organisations’).
- Sleeping Well; Tiredness; Sleep and Tiredness: Key Facts and other factsheets available from the Royal College of Psychiatrists website at www.rcpsych.ac.uk.
Useful organisations

Afasic
Helpline: 0300 666 9410
Web: www.afasic.org.uk

ASSIST Trauma Care
Helpline: 01788 560 800
Web: www.assisttraumacare.org.uk

Brain and Spinal Injury Charity (BASIC)
Helpline: 0870 750 0000
Email: enquiries@basiccharity.org.uk
Web: www.basiccharity.org.uk

Brain and Spine Foundation
Helpline: 0808 808 1000
Email: helpline@brainandspine.org.uk
Web: www.brainandspine.org.uk

Brain Tumour Charity, The
Tel: 0808 800 0004
Email: support@thebraintumourcharity.org
Web: www.thebraintumourcharity.org

British Association of Occupational Therapists and College of Occupational Therapists
Tel: 020 7357 6480
Email: reception@cot.co.uk
Web: www.cot.co.uk

British Sleep Society
Tel: 01543 442 156
Email: admin@sleepsociety.org.uk

Cerebra
Helpline: 0800 328 1159
Email: info@cerebra.org.uk
Web: www.cerebra.org.uk

Child Brain Injury Trust
Helpline: 0303 303 2248
Email: helpline@cbit.org.uk
Web: www.childbraininjurytrust.org.uk
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<td>Edinburgh Sleep Centre</td>
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<td>Encephalitis Society</td>
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Meningitis Research Foundation
Helpline (24hr): 0808 800 3344
Email: info@meningitis.org
Web: www.meningitis.org

Mind
Infoline: 0300 123 3393
Email: info@mind.org.uk
Web: www.mind.org.uk

Papworth Respiratory Support and Sleep Centre
Information line: 01480 364137
Web: www.papworthrssc.nhs.uk

Pituitary Foundation, The
Helpline: 0845 450 0375
Email: helpline@pituitary.org.uk
Web: www.pituitary.org.uk

Stroke Association
Helpline: 0303 3033 100
Email: info@stroke.org.uk
Web: www.stroke.org.uk
Glossary

- **Ascending reticular activating system (ARAS)**
  The brain system believed to be responsible for alertness and motivation. It connects the brain stem to higher areas of the brain, such as the hypothalamus, thalamus and cerebral cortex.

- **Brain stem**
  The lower extension of the brain where it connects to the spinal cord. Neurological functions located in the brain stem include those necessary for survival (breathing, heart rate) and for arousal (being awake and alert).

- **Carbohydrates**
  A group of organic compounds, including sugars and starches, which constitute one of the major sources of energy for the body.

- **Cerebellum**
  Located at the back of the brain between the cerebrum and the brain stem. The cerebellum is responsible for the co-ordination of movement and balance.

- **Cerebral cortex**
  The highly evolved outer layer of the brain. Involved in higher brain functions including consciousness, memory, learning and movement. Includes areas that regulate both sensory and motor functions and is divided into the frontal, parietal, temporal and occipital lobes.
**Cerebrum**
The largest part of the brain, which is composed of the two cerebral hemispheres.

**Clinical psychologist**
A professional who aims to reduce psychological distress and enhance and promote psychological well-being.

**Cognitive behavioural therapy (CBT)**
A form of talking therapy that focuses on changing negative patterns of thinking and behaviour.

**Corpus callosum**
The bundle of nerve fibres that connects the left and right hemispheres of the brain and communicates information between them.

**Hypothalamus**
The part of the brain responsible for maintaining the internal environment of the body by regulating body temperature, blood pressure, thirst, hunger and the sleep-wake cycle. The hypothalamus controls the activity of the pituitary gland.

**Medulla**
The region of the brain stem that is responsible for controlling automatic processes such as breathing and heart rate.
Managing fatigue after brain injury

■ **Midbrain**
The region of the brain that controls the body’s responses to sensory information, especially visual and auditory information.

■ **Mindfulness**
A meditation technique in which a person makes a conscious effort to focus on their own thoughts, feelings and the world around them.

■ **Occupational therapist**
A professional who is involved in the assessment and rehabilitation of physical and psychological conditions, using specific purposeful activity to prevent disability and promote independent functioning in all aspects of daily life.

■ **Pacing**
A way of balancing and spreading activities throughout the week.

■ **Pituitary gland**
A small gland, situated at the base of the brain, which secretes hormones into the bloodstream. It is controlled by the hypothalamus and the hormones it produces regulate the hormone production of other glands in the body.

■ **Pons**
Structure located in the brain stem that relays sensory information between the cerebellum and cerebrum. It plays a role in arousal and regulating respiration.
■ **Protein**
An important part of the structure of all living cells. Essential for the growth, maintenance and repair of body tissues. Obtained in the diet from foods such as meat, fish, dairy products, beans and nuts.

■ **Sleep hygiene**
Involves having a regular routine in order to prepare the body for sleep.

■ **Thalamus**
The area of the brain that processes sensory information and relays it to the cerebral cortex. It is connected to the ARAS and plays a key role in regulating states of sleep and wakefulness.

■ **Ventricles**
Cavities (spaces) inside the brain which contain cerebrospinal fluid.
The Oliver Zangwill Centre for Neuropsychological Rehabilitation is part of Cambridgeshire Community Services NHS Trust. It provides high-quality rehabilitation for the cognitive, social, emotional and physical needs of people with acquired brain injury.

The Centre offers a unique (to the UK) holistic and intensive assessment and therapy programme. We also aim to meet the needs of families of brain injured people.

Our ultimate aim is to promote the maximum level of:
- understanding the consequences of brain injury;
- independent functioning in the home and community;
- productive activity, including work.

In partnership with clients, families and other services, and through our links with the Medical Research Council and the NHS Research & Development Initiative, we seek to apply the latest research findings, evaluate our service and investigate ways to improve neuropsychological rehabilitation.

For more information go to www.ozc.nhs.uk or contact us at:

- The Oliver Zangwill Centre for Neuropsychological Rehabilitation
  Princess of Wales Hospital
  Lynn Road, Ely
  Cambs CB6 1DN
  Telephone: 01353 652165
  Fax: 01353 652164
  Email: enquiries@ozc.nhs.uk
About the authors

Donna Malley is an Occupational Therapy Clinical Specialist at the Oliver Zangwill Centre, Ely. Jacqui Wheatcroft (née Cooper) is a Senior Occupational Therapist at Caulfield Hospital in Victoria, Australia. Jacqui formerly worked as Senior Occupational Therapist at the Oliver Zangwill Centre. 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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- the people we have worked with who have shared their experiences with us following their brain injury.
The cerebral cortex

**Parietal lobe**
Perception, spatial awareness, manipulating objects, spelling

**Wernicke’s area**
Understanding language

**Broca’s area**
Expressing language

**Occipital lobe**
Vision

**Frontal lobe**
Planning, organising, emotional and behavioural control, personality, problem solving, attention, social skills, flexible thinking and conscious movement

**Temporal lobe**
Memory, recognising faces, generating emotions, language
About Headway

Headway – the brain injury association is a charity set up to give help and support to people affected by brain injury.

A network of local Headway groups and branches throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems. Other services provided by Headway include:

- Supporting and developing local groups and branches
- Promoting understanding of brain injury and its effects
- An award-winning range of publications on aspects of brain injury
- Accreditation of UK care providers through the Approved Provider scheme
- A comprehensive, award-winning website
- Campaigning for measures that will reduce the incidence of brain injury
- Providing grants from our Emergency Fund for families coping with financial difficulties
- Headway Acute Trauma Support (HATS) nurses to support families with loved ones in hospital

Freephone helpline: 0808 800 2244
(Monday–Friday, 9am–5pm)
Telephone: 0115 924 0800
Website: www.headway.org.uk
Fax: 0115 958 4446
Email: helpline@headway.org.uk
Managing fatigue after brain injury

Jacqui Wheatcroft, Donna Malley and Richard Morris

This booklet 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 your fatigue and how it affects you. Managing fatigue is not about taking it away but taking control of it.

Website: www.headway.org.uk
Helpline: 0808 800 2244