

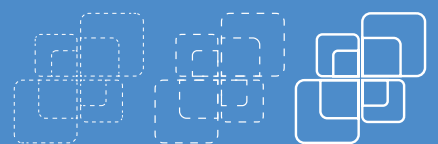


**National Rehabilitation
University Hospital**

An tOspidéal Náisiúnta Athshlánúcháin

FATIGUE

A Manageable Challenge Following Brain Injury





FATIGUE

A Manageable Challenge Following Brain Injury

Patient Name: _____

Date: _____

Managing Fatigue after Brain Injury

This booklet has been written for people who have had a brain injury and are experiencing fatigue. This information aims to help you, your family and friends to understand the fatigue related to your brain injury and how it affects you. Fatigue management is not about taking away your fatigue but rather about helping you take control of it, and finding ways of managing it.

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Fatigue Questionnaire

The statements that follow may apply to your own situation. The aim of this questionnaire is to help you, by completing it, to get a better understanding of your fatigue. You could share the findings with your friends and family so they can better understand what you are experiencing. Along with your therapist, choose the answer that best matches your experience of fatigue due to your brain injury, over the past month. Try not to think too long before choosing an answer. Please read each item carefully then circle the answer that best describes how you experience fatigue.

How often do you experience fatigue?

Fatigue caused problems for me before my brain injury.	Yes	No		
The fatigue I now experience is different in severity than before my brain injury.	True	False		
How frequently do you experience fatigue?	All the time	Daily	Weekly	
At what time of the day do you experience fatigue?	Morning	Afternoon	Evening	Night
How long does your fatigue last?	Less than an hour	Less than three hours	All day	
Is the frequency of your fatigue unpredictable - does it occur unexpectedly for no reason?	Yes	No		

How does fatigue impact on your life?

Below are statements that describe how people sometimes feel when they are fatigued. Please read each item carefully then circle the number that best describes how you experience fatigue.

0 = Not at all

1 = A little

2 = Moderately

3 = A lot

4 = Extremely

Fatigue interferes with my ability to do things that are important to me.	0	1	2	3	4
Fatigue interferes with my work.	0	1	2	3	4
I participate less frequently in social activities due to my fatigue.	0	1	2	3	4
Fatigue interferes with my family life.	0	1	2	3	4
Fatigue interferes with my ability to engage in recreational activities.	0	1	2	3	4
Fatigue interferes with my ability to engage in sexual activities.	0	1	2	3	4
Fatigue interferes with my ability to shop and do errands.	0	1	2	3	4
Fatigue interferes with my ability to do housework.	0	1	2	3	4
Fatigue interferes with my ability to take care of my personal needs, for example, washing or showering.	0	1	2	3	4

How do you feel when you are fatigued?

Below are statements that describe how people sometimes feel when they are fatigued. Please read each item carefully, then circle the number that best describes how you experience fatigue.

0 = Not at all 1 = A little 2 = Moderately 3 = A lot 4 = Extremely

Thinking Problems: When I am fatigued...

I am forgetful	0	1	2	3	4
I am confused	0	1	2	3	4
I have trouble paying attention	0	1	2	3	4
I make more mistakes than usual	0	1	2	3	4
I am unable to learn new things	0	1	2	3	4
I cannot think quickly	0	1	2	3	4
I cannot think clearly	0	1	2	3	4

Physical Problems: When I am fatigued...

My muscles ache	0	1	2	3	4
My legs feel weak	0	1	2	3	4
My head feels heavy	0	1	2	3	4
My arms feel weak	0	1	2	3	4
I ache all over	0	1	2	3	4

0 = Not at all

1 = A little

2 = Moderately

3 = A lot

4 = Extremely

Emotional Problems: When I am fatigued...

I feel upset	0	1	2	3	4
I feel nervous	0	1	2	3	4
I feel sad	0	1	2	3	4
I feel unmotivated	0	1	2	3	4
I feel tense	0	1	2	3	4
I feel distressed	0	1	2	3	4
I am short tempered	0	1	2	3	4

What triggers your fatigue?

Please answer these statements about what you feel triggers your fatigue.

Doing routine daily activities, for example, showering brings on my fatigue	True	False
Exercise brings on my fatigue	True	False
Stress brings on my fatigue	True	False
Long periods of inactivity bring on my fatigue	True	False
Depression brings on my fatigue	True	False
I feel that my medicines cause me to be fatigued	True	False
I am only fatigued if I don't sleep well at night	True	False

What helps when you are fatigued?

Please answer these statements about what you feel lessens your fatigue.

Resting lessens my fatigue	True	False
Sleeping lessens my fatigue	True	False
Cool temperatures lessen my fatigue	True	False
Positive experiences lessen my fatigue	True	False
Eating or drinking something lessens my fatigue	True	False
Exercise lessens my fatigue	True	False

What is Fatigue?

Fatigue is experienced by most people following a period of physical or mental activity. It is usually a sign telling us to stop and take a break. 'Normal' fatigue is usually a temporary state and is lessened by a period of rest. Pathological fatigue following a brain injury may be present most of the time and is likely to significantly impact on a person's ability to engage in the activities they want to do.

Why do you experience Fatigue after Brain Injury?

Everyone's experience of fatigue following a brain injury is different. It can affect a person in many ways. Fatigue can reduce your enjoyment of life and impact on your ability to participate in rehabilitation. Some people feel an overwhelming sense of tiredness that results in them being unable to participate in activities. Others may feel lethargic, lacking energy and feeling unable to motivate themselves. Fatigue may worsen difficulties associated with brain injury including; attention, memory, pain and physical weakness.

Did you know?

- Of the difficulties resulting from a brain injury, fatigue is one of the most common symptoms, reported in up to 80% of the population (Borger et al., 2005)
- Literature suggests that many individuals who have sustained a brain injury view fatigue as their most challenging symptom (LaChapelle et al., 1998)
- As many as 73% of individuals complain of fatigue up to 5 years after sustaining a brain injury (Olver et al., 1996).

Fatigue related to brain injury can affect:

How a person feels

- "This tiredness is bone crushing... I've no control over it"
- "I shouldn't feel like this"
- "What is wrong with me?"
- "People think I'm being lazy - nobody understands!"
- "I feel guilty"

How a person thinks

- "I'm thinking through a fog"
- "I'm listening to what people say but I cannot take it in"
- "I can't go to my local pub anymore, it's too loud"

What a person does

- "I cannot return to work because of this tiredness"
- "My husband and children have to do so much more"
- "I can't keep up with my toddler in the playground anymore"
- "I no longer have the energy to do the things I used to enjoy - walking the dog is out"
- "My speech becomes slurred when I'm tired"

What are the triggers to fatigue?

There are many potential triggers or causes of fatigue following brain injury. If you recognise your triggers it will help you cope better with fatigue. Some common triggers of fatigue and some possible solutions are detailed below.

Mood and Fatigue

“I feel so down. Why has this happened to me?”

Anxiety, depression, stress and tension can all contribute to fatigue. You may find your mind is racing at night when you try to sleep, you may find yourself crying more frequently or feeling anxious in crowded environments.

Managing your mood can play an important role in combating fatigue. Here are tips to help keep your mood in check:

- **Adjust your expectations:** For example, if you have a list of 10 things you want to accomplish today, narrow it down to two and leave the rest for other days. A sense of accomplishment goes a long way to feeling in control of your mood.
- **Help others understand and support you:** Family and friends can be helpful if they can ‘put themselves in your shoes’ and understand what fatigue means to you. Support groups can be a source of comfort as well. Other people who have suffered a brain injury understand what you are going through.
- **Relaxation techniques:** Recordings or podcasts that teach deep breathing, or visualization can help reduce stress.
- **Participate in activities that divert your attention away from fatigue:** For example, activities such as knitting, reading, or listening to music require attention but little physical energy.

If your mood seems out of control, talk to your doctor, a counsellor or a psychologist. They are there to help.

Medication

Medication has been found to be useful in managing other triggers associated with your brain injury, such as antidepressants for low mood. However, medication can also increase your fatigue due to side effects, such as drowsiness.



There are also medications available that can target fatigue specifically. It is important to consult your doctor to ask about any benefits of medication and possible alternatives.

Nutrition

Sometimes when we are tired we crave sweet food and drinks to give us extra energy. These can be foods like chocolate, biscuits and fizzy drinks. These types of food can cause weight gain, and being overweight can cause you to be tired. It is important to know when you are tired rather than hungry. Often we eat for a variety of reasons apart from hunger. Physical hunger gives you a rumbling feeling in your belly. If this signal is not there it is important to ask yourself, "Am I really hungry or am I tired, bored or fed up?"

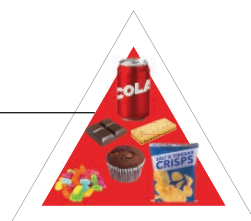
Here are some tips;

- Eat regular meals, such as breakfast, lunch and dinner. Have fruit in between meals if hungry.
- Eat slowly without distractions such as watching TV and reading.
- Pick foods from each of the shelves of the food pyramid and limit those from the top.
- It is important to drink at least 8 -10 glasses of fluid per day. This can include tea, coffee and low sugar or diet drinks.
- Limit alcohol intake as it can affect how your brain functions, resulting in feelings of fatigue and interfering with your normal sleep pattern. Alcohol may also interact with the medications you are taking. Especially following a brain injury, it is important to speak to your doctor about alcohol.

It is important to talk to your dietitian if you have questions about your diet.

The Food Pyramid

Foods and drinks high in fat, sugar and salt



Fats, spreads and oils



Meat, poultry, fish, eggs, beans and nuts



Milk, yogurt and cheese



Wholemeal cereals and breads, potatoes, pasta and rice



Vegetables, salad and fruit



What are the triggers to fatigue? (continued)

Sleep

“I often wake up feeling like I haven’t slept at all”

Sleeping well is very important and may help to reduce fatigue. Pain, continence problems, the hospital unit environment and stress are some of the factors that can prevent you from getting adequate sleep at night. Fatigue following brain injury can cause you to sleep during the day and result in being unable to sleep at night. It is very important to develop good ‘sleep hygiene’ or a regular sleep routine which will help you get a good night’s sleep and feel more alert on waking.

Good ‘sleep hygiene’ means;

- Having a sleep routine - going to bed and getting up at the same time. Some people find it helps to have a warm drink before bed.
- Using your bed for sleeping only, not for eating or watching television.
- Avoid drinking alcohol or caffeine, smoking or eating heavy meals before bedtime.
- Create a comfortable room in which to sleep - put away clutter, use blackout blinds and ear plugs, regulate the temperature of the room.
- Avoid stress and worry at bedtime - use relaxation techniques, count sheep, keep a notebook by your bed to write down any thoughts which can be dealt with the next day.
- Frequent, short rests may be beneficial during the day but avoid taking a nap after 4pm.
- Be sure to get exposure to sunlight or fresh air and some form of exercise during your day.
- Don’t exercise within three hours of going to bed.



What are the triggers to fatigue? (continued)

Exercise

The physical problems experienced after your brain injury may have resulted in decreased physical activity which can lead to tiredness and lack of energy. Scientists have found that even healthy athletes forced to spend extended periods in bed or sitting in chairs develop feelings of anxiety, depression, weakness, fatigue, and nausea. Regular, moderate exercise can decrease these feelings and help you stay active.

Regular exercise can also help prevent obesity and cardiovascular or heart disease. Your physiotherapist or sports therapist will be able to advise you about what exercise is best suited to you.

It is important to;

- Plan some form of exercise into every day. This could include walking to the bus stop, washing the windows, taking the stairs instead of a lift, hoovering or going for a swim.
- Drink plenty of fluids before, during and after heavy exercise.
- Monitor the effect different exercises have on your fatigue and adjust your exercise accordingly.
- To make exercise more enjoyable try to engage in a range of different activities such as bowling, sailing, and Wii computer games or jumping on a trampoline!



Mental Exertion

“I can’t focus on my computer screen -
I keep looking out the window at passers by”

Often following a brain injury, people find they need more mental effort to perform a task that was once easy to do. Some people report experiencing their brain “shutting off” or that their thoughts are foggy. Others can be overwhelmed in busy environments or feel highly distracted. When you are tired you may also find that you are more forgetful.

As everyone experiences different changes in their mental or cognitive or thinking skills, it can be helpful to discuss management strategies with your Occupational Therapist, Speech and Language Therapist or Psychologist.

Some cognitive, thinking or mental strategies that are commonly used include;

- **Get organised** - use a wall calendar or planner to take note of all upcoming appointments and activities to be completed each day.
- **Take frequent breaks** - do not work on mentally demanding activities for more than one hour without a break.
- **One thing at a time** - do not try to take on too much at once - do one thing and then move on to the next.
- **Best time** - most people find it best to complete mentally challenging work in the morning.
- **Minimise distractions** - try to work in a quiet environment with no background distractions.
- **When socialising** - limit your group conversation to two or three people.

How can I conserve my energy?

Think of your body as a bank. Your energy deposits come from what you eat and by resting. Your energy deposits are very precious. If you suffer from fatigue you should spend them wisely.

By conserving your energy bank you can do all the activities you need to do and enjoy doing. When managing your energy deposit you should consider;

- **Pacing** - this is a way of spreading out activities throughout the week to prevent you from spending all your energy in one go.
- **Planning** your day or week ahead, aiming to do a little each day rather than all in one go.
- **Resting** regularly for short periods during the day - this may not mean lying down, but rather having some quiet time with no demands. You should rest before you become exhausted.
- **Prioritising** - you may have to accept the fact that you will not be able to do everything you used to do. When prioritising ask yourself the following questions;
 1. Which activities are most important?
 2. Which activities are essential?
 3. Which activities do you enjoy?
 4. Which activities could you delegate to someone else?
 5. Which activities could you do less often?

To conserve energy you will need to be flexible and creative in how you approach everyday activities. Discuss the problems you are experiencing with your Occupational Therapist and you will be able to come up with some effective solutions together.

Here are some commonly used tips that will help you conserve your energy during everyday activities.

Housework

- Keep heavy appliances or frequently used utensils on counter tops to minimize the need to stretch, bend and carry.
- Employ a cleaner. If you cannot afford one, talk to your social worker. You may be entitled to a home help.
- Sit down to do whatever chores you can, for example, peeling vegetables, ironing or washing dishes.
- Use a lightweight iron and a heatproof pad. Iron essential items only.
- Prepare meals when feeling less tired. Make up double portions so you can freeze half later.
- Ask someone else to take out the rubbish and lift heavy items from the oven.
- Alternate heavy cleaning tasks with light ones and do one main job each day rather than doing an entire weeks cleaning at one time.
- Line baking pans with foil to minimise cleanup.
- Use a basket to carry cleaning supplies between rooms to avoid making multiple trips.
- Place all dirty laundry in one central location, complete washes regularly and lower your clothes line to shoulder length to avoid over reaching.
- Reduce the amount of grass and flower bedding in your garden by replacing with low maintenance chippings or flagstones.



How can I conserve my energy? (continued)

Shopping and Community Jobs

- Shop online or ring your local shop and get food delivered to your home.
- Complete banking online, including paying bills
- If going to the shop bring a shopping list categorised by where the products are located, for example dairy, fruit and vegetables, meat, cleaning products.
- Use a roller bag to transport shopping rather than carrying bags.
- You may be entitled to a Disabled Parking Card available through the Irish Wheelchair Association (IWA) which means you can park near the front entrance of buildings. Ask your occupational therapist about this.



Childcare

- Explain to your children that you are feeling tired and will not be able to do as much with them as before.
- Plan activities with your children that can be done sitting down - reading a book, watching a film, playing a board game.
- Go to places where you can sit down while children enjoy themselves.
- Do not lift and carry small children. Use a pram if you have to transport them.
- Ask your children to help with light chores around the house.
- Accept help from others to take your children to and from school.
- Kneel while washing a child in the bathtub or sit on a low stool.
- Wash, change and dress an infant at counter height.
- Adapt the fastenings on your children's clothes for easier dressing.



Work

- Discuss with your employer or human resource manager flexible hours of work.
- Change your hours so that you can travel to and from work at less busy times.
- Have a parking space allocated close to the front entrance.
- Take short breaks throughout the day when you can lie down and rest.
- Work from home on alternative days.
- Arrange your desk and chair heights to help maintain proper posture. This will help to reduce slumping of the shoulders and neck flexion.
- Use a phone device that allows your hands to be free during long conversations.



Personal Care

- Lay out clothes for the next day before going to bed.
- Sit while dressing and washing wherever possible.
- Dress the weaker side first then the stronger side. When undressing undress the stronger side first then the weaker side.
- Use a long handled shoe horn or reacher.
- Keep shampoos, soaps, razor by the shower or bath.
- Avoid very hot water when showering as this can increase fatigue.



Useful Contacts and Resources

Acquired Brain Injury Ireland

Acquired Brain Injury Ireland provide flexible and tailor-made services for people with an acquired brain injury enabling people with brain injury to live an independent life within the community.

Telephone: 01 280 4164

Website: www.abiireland.ie

Headway

Headway provides support and services to people affected by brain injury. It also works to heighten public and political awareness of acquired brain injury (ABI) and the impact it has on individuals, families and carers. Headway often run fatigue management programmes.

Helpline: 1800 400 478

Website: www.headway.ie

Brain and Spine Foundation

Brain and Spine Foundation provide information and support for adults and children affected by neurological conditions. They have produced an online guide to coping with fatigue, for people affected by brain injury, brain haemorrhage, MS and other brain and spine conditions.

Helpline: 00 44 808 808 1000

Website: www.brainandspine.org.uk

Publications

Cooper, J. & Malley, D. (2008) Managing Fatigue after Brain Injury. Headway Publication.

How can you manage your fatigue?

Use your experience along with information from this booklet to answer the following statements:

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

The factors that trigger my fatigue are...

When I get fatigued I feel...

I can manage my fatigue by...

References

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- La Chapelle DL, Finlayson MA. An evaluation of subjective and objective measures of fatigue in patients with brain injury and healthy controls. *Brain Injury*. 1998;12:649-659 as cited in In Cantor JB, Ashman T, Gordon W, Ginsberg A, Engmann C, Egan M, Spielman L, Dijkers M, Flanagan S (2008) Fatigue after TBI and its impact on participation and Quality of life. *Journal of Head Trauma Rehabilitation* 23 (1) 41-51
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NRH Services Include:

Spinal Cord System of Care Programme

Brain Injury Programme

Stroke Specialty Programme

Prosthetic, Orthotic & Limb Absence Rehabilitation (POLAR) Programme

Paediatric Family-Centered Rehabilitation Programme