Fatigue Management Manual



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Understanding Fatigue

- What is meant by fatigue
- Causes of fatigue
- Measuring your fatigue
- Analysing your fatigue

Building a Toolkit

- Getting better sleep
- Pacing, resting, prioritising and scheduling
- Relaxation and stress management
- Exercise and diet
- Change and acceptance
- Goal setting for effective change

Why Fatigue Management?

- Learn a new pace of living
- Take steps to lessen the impact of fatigue
- Make the most of what you *can* do, rather than focusing on what you can't.

Understanding Fatigue

Fatigue is a **physical, emotional and/or mental tiredness**. It is often experienced as overwhelming. It is very different from everyday tiredness. It has a big influence on everyday activities and can make even small chores or routine tasks seem impossible to do.

Fatigue is known to be one of the most difficult side-effects of neurological conditions. If you are struggling, you are not alone.

CAUSES OF FATIGUE

We don't know the precise causes of fatigue. Because of the physical, emotional and mental aspects of fatigue, the cause is likely a combination of factors.

Fatigue can be associated with any brain injury, whatever the cause (e.g. stroke, trauma, inflammation or tumour) and wherever the location within the brain. Pain and certain medications, such as anti-epileptic drugs, can also cause fatigue. Emotional side-effects of any injury or treatment (such as worry, anxiety, depression, and having trouble sleeping) can make fatigue even worse.

If you think you have fatigue, you could also request a medical evaluation to identify possible medical reasons for this (e.g. vitamin deficiencies).

SUGGESTED HANDOUTS:

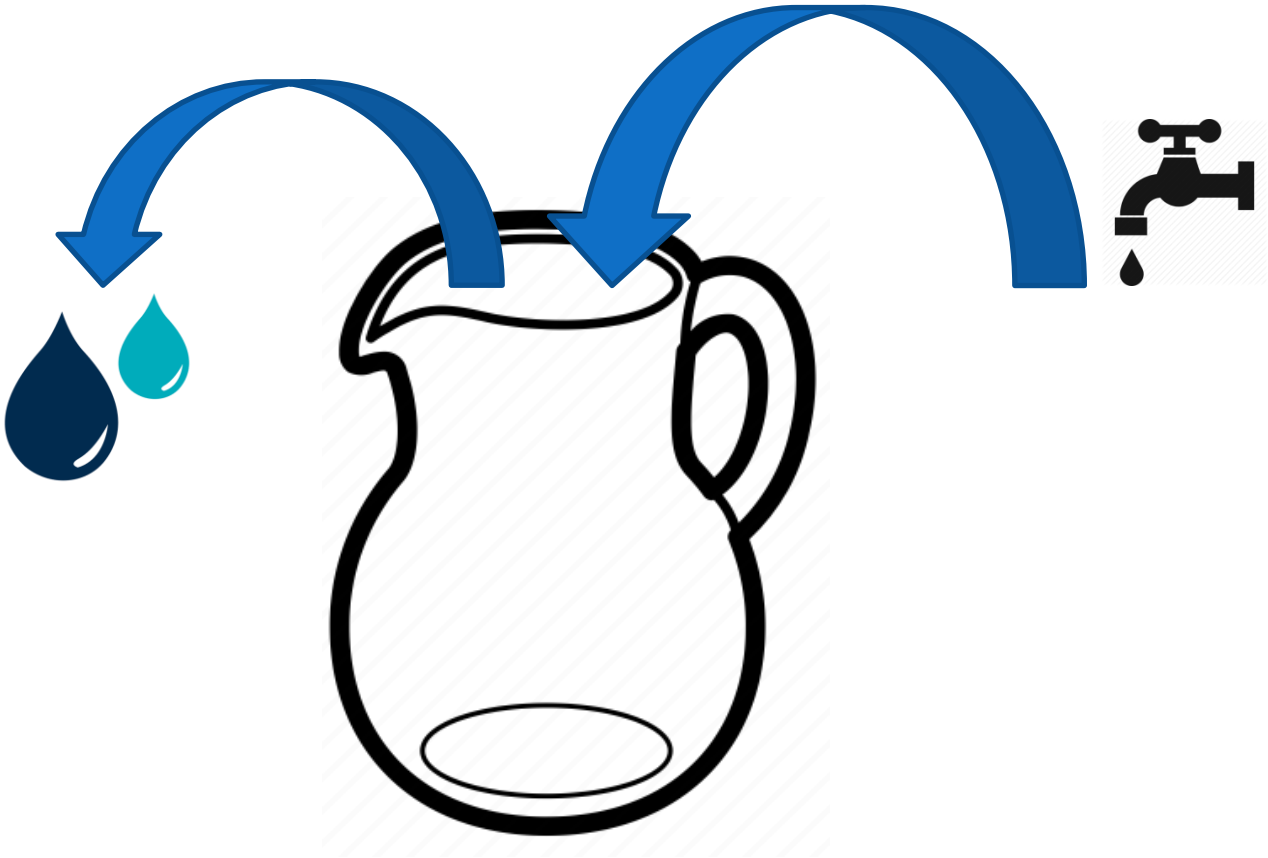
Fatigue Diary

Jug of Life

Think of the jug below as your energy supply during the day.
Your jug might now be smaller than it used to be.

Think about the things that empty your jug (e.g. busy environment; walking…)?
How do you replenish your jug (e.g. quiet time; herbal tea…)?

List as many things as you can on the diagram below:

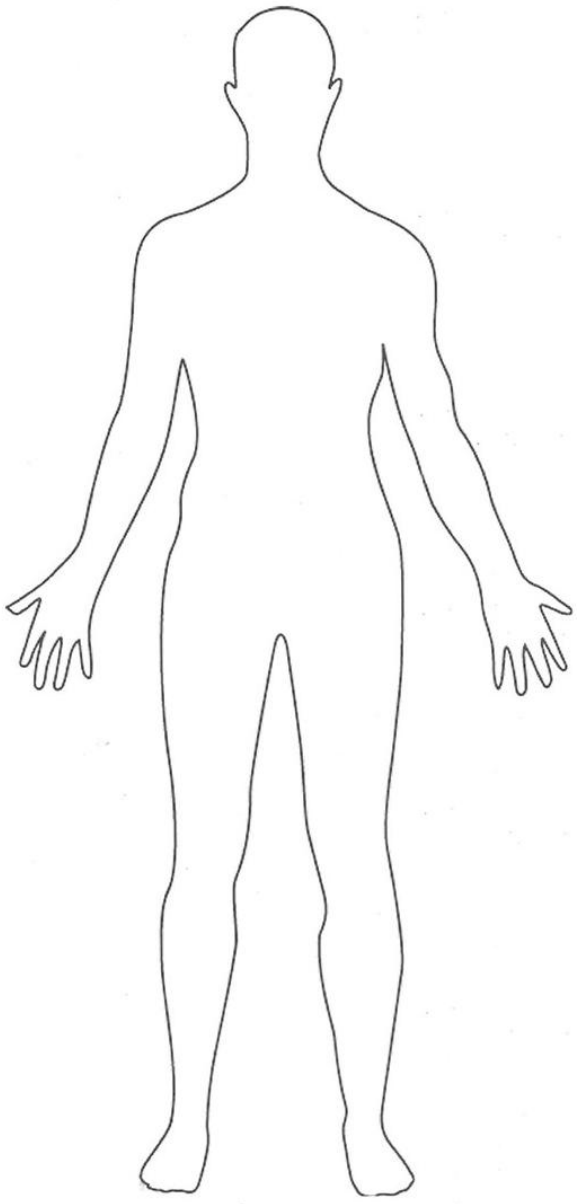


TOP TIP:

It might be useful to stick this sheet where you (and members of your family) can see it.

Body Map

In order to cope with fatigue you must first be able to recognise it.
What does your fatigue feel like? Mentally? Physically? Emotionally? Behaviourally?
Label the diagram below.



TOP TIP:

It might be useful to stick this sheet where you (and members of your family) can see it.

Adapted from the Brain Injury Rehabilitation Workbook, by Wilson, Winston and Bateman (2016)

Understanding Fatigue, continued.



ANALYSING YOUR FATIGUE

Analysing your fatigue by keeping a **fatigue diary** for *at least a week* is the best way to find strategies to manage it. Study your fatigue diary and ask yourself the following questions (or discuss with your therapist):

Can you spot any **patterns** in your fatigue diary?	
Are there **particular activities** that make you especially fatigued?	
Are there **particular times** in the day that you are most fatigued?	
Are you taking enough **rests**? Are you taking them at the best time?	
Are you **getting up and going to bed** at the same time each day?	
Are you **sleeping in the day**? Does this affect your sleep at night?	
Are you able to do **activities that you enjoy**?	
Are there activities that you could **delegate** to others?	
Are you **re-filling your jug** enough throughout the day?	
What number should let your fatigue reach before you rest?	
What could be the **'quick fixes'**?	

Your Fatigue Management Toolkit

Hopefully you now understand your fatigue a little better. There is a lot you can do to help manage your fatigue now that you have a better understanding of it.

Now you can begin to build your **Fatigue Management Toolkit** to help deal with all the things that don't help.

Your Fatigue Management Toolkit will cover the following areas:

1. Getting better sleep
2. Pacing, resting, prioritising and scheduling
3. Relaxation and stress management
4. Exercise and diet
5. Change and acceptance
6. Goal setting for effective change



Getting Better Sleep

How often do you do the following?

Positive influences on sleep:	*usually sometimes rarely*	Negative influences on sleep:	*usually sometimes rarely*
Going to bed at the same time		Use electronic devices before bed	
Getting up at the same time		Nap during the day / evening	
Exercise every day		Eat heavy/rich meal before bed	
Getting fresh air / natural light during the day		Drink alcohol before bed	
Keeping the bedroom cool		Drink caffeine after 3pm	
Keeping the bedroom dark		Fizzy drinks / sugar before bed	
Keeping the bedroom quiet		Smoking before bed	
Do a relaxation exercise before going to bed		Going to bed hungry / eating too much before bed	
Keep your hands and feet warm		Get annoyed with yourself for not being able to sleep	

*Questionnaire adapted from the Brains Trust fatigue management book

Set goals for better sleep.

If the answers to the questionnaire highlight some areas that you could improve, set yourself up to three goals to achieve over the next 2 weeks.

1	
2	
3	

Look back at these goals with your therapist at your next session.

You can change your goals if you need to; and you can make new goals once the ones above have been achieved.

SUGGESTED HANDOUTS:

Centre for Clinical Interventions Sleep hygiene information

Get a Good night's Sleep workbook

Prioritising

Often when we are fatigued, things that we would normally deal with become overwhelming. We sometimes feel unable to cope. This sets off a **negative cycle** – the more we feel overwhelmed, the more fatigued we feel.

Prioritising activities means that you can save your energy for the things that you need and want to do. This might also mean letting go of some of the things that you can't do, or finding workarounds.

Prioritisation activity.

This activity will help you to prioritise. You need four different-coloured highlighters.

List ALL the activities you do in a typical week (or day) on the table over-leaf.

Now, work through your list, highlighting in different colours:

1. which activities are very important to you to keep doing
2. which activities would you rather not do
3. which activities could be done less often
4. which activities don't really need to be done at all

Also ask yourself:

- *Could any activities be done in a more energy-efficient way?*
- *Could they be done at a different time?*
- *Could they be done less often, or for less amount of time?*
- *Can anyone or anything help you with these activities?*

Prioritisation activity:

Self-care activities	Productive activities	Leisure activities

Boom & Bust cycle

Do you recognise the **boom & bust cycle** illustrated below:



Diagram above from the Brains Trust Fatigue Management Manual

Boom is the day (or time) when you feel a bit more energetic. You might try to make up for lost time by packing in as much as you can. You might become unaware of, or *ignore,* the signs of fatigue or increased pain. It is almost as if your mind takes over, racing ahead as your body is left behind.

But, your body may not be able to deliver what you are asking of it. You may not have the ability your mind expects or is used to. Inevitably, you crash and need to rest to recover. This is the '**bust**' phase. Over time this can become a difficult downward spiral.

There are strategies to help to break this cycle.

Just recognising this pattern of boom and bust will help you to break it and pace yourself a little differently.

Pacing & Activity Scheduling

Now that you have prioritised you daily/weekly activities, you can begin to plan your time more effectively. This might seem like overkill, but by doing this you'll be able to manage your energy levels better. Prioritising and planning your days and weeks will eventually mean that you will be more consistent with what you can do, and over time you will be able to do MORE.

How to pace yourself:

Work out your BASELINE (what can you manage without increasing negative symptoms, at least most of the time). E.g. if you know that 20mins of walking tires you out, then around 10-15minutes might be your baseline.

The traffic light system can be a useful way to think about the demand of certain activities or tasks. Thinking about activities in this way can help you to plan your day. Remember to think of the COGNITIVE and EMOTIONAL demands of activities, as well as the PHYSICAL demands.



RED: Demanding activities

AMBER: Moderate activities

GREEN: Light / relaxing activities

You could create an example weekly activity schedule and colour the activities accordingly. Then you can see how your week looks in colour. Consider breaking long periods of 'red activities' with some 'green activities'; or inserting some red or amber activities into long stretches of green. Always think of your PRIORITIES!

Pacing up can occur once your routine is stabilised and working for you. Decide on a realistic build up rate and take this slow and steady. Monitor your fatigue and adapt accordingly.

The Golden Rules to avoid Boom/Bust:



Balance your days with easier and trickier tasks.
Build in rest breaks.



Break activities down into smaller chunks.



Learn to stop BEFORE fatigue forces you to stop.
It should still feel like you *could* do more – but DON'T!



Plan and prioritise over hours, days and even weeks.

Common difficulties with pacing include:

"I got so involved I lost track of time"

Pacing takes practice, but you need to stop BEFORE your fatigue forces you to for this technique to work. Use a clock or alarm to help you with this.

"I don't know how long to break for or what to do"

Change your position, posture and location if you can. Do something relaxing, but try not to just stop and do nothing. Walk around, do some stretches, get some fresh air, listen to the radio… Some activities need long breaks; others will only require short breaks.

"I make decisions based on how I'm feeling at the time and I don't like planning"

This forms part of the boom-bust cycle that it is important to try to avoid as it means you do more on good days but then suffer the consequences (often leading to achieving less over-all).

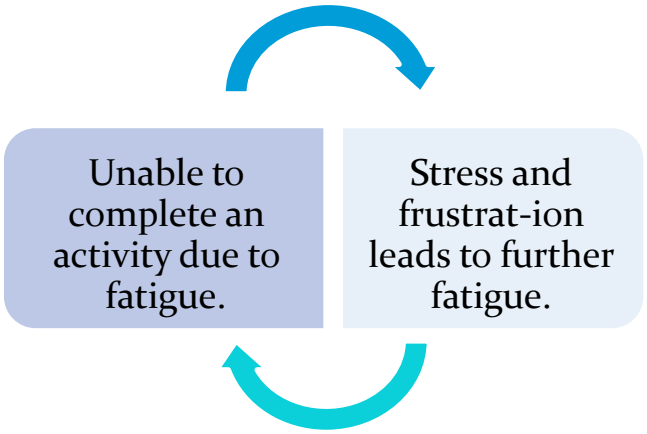
SUGGESTED HANDOUTS:

Weekly activity template
Lifestyle Top Tips
Activities List

Stress Management & Relaxation

Feeling tired or unwell can make us feel stressed and under pressure. Not being able to do what we expect our bodies to be able to do can lead us to feel even more frustrated and stressed with ourselves and others.

Stress, frustration and anger are all draining emotions. These emotions demand a lot from our bodies and will contribute to the primary neurological fatigue you are already experiencing. It is a negative cycle that needs to be broken.



So, how can you manage your stress levels better?

- Ensure your days and weeks are balanced – work, rest and play.
- Learn relaxation strategies which work for you and put them into regular practice.
- Talk to others and gain support; this includes family, friends and work colleagues or managers.
- Use your prioritisation and planning skills, and make sure to prioritise some pleasurable activities.
- Learn some skills to challenge any unhelpful thinking patterns.

SUGGESTED HANDOUTS:
Fight / Flight response to stress
How do I know if I am Stressed?

Relaxation

Relaxation doesn't just happen – it's a skill, and some people are better at it than others! You might need to develop your ability to relax, through breathing exercises and/or different types of physical relaxation.

Relaxation is a process that decreases the effects of stress on your mind and body. Relaxation has many benefits:

- lowers the heart rate and blood pressure
- slows breathing rate
- increases blood flow to major muscles
- reduces muscle tension and pain
- reduces anger and frustration; boosts confidence and mood
- improves sleep
- reduces the activity of stress hormones

Types of relaxation to try:

Progressive Muscle Relaxation
Visualisations
Deep breathing / abdominal breathing
Massage / reflexology
Tai Chi / Yoga
Aromatherapy
Meditation
Mindfulness



Remember that relaxation techniques are skills. As with any skill, your ability to relax improves with practice. **Be patient with yourself**. As your ability to relax improves, the benefits will become much clearer.

SUGGESTED HANDOUTS:
Abdominal Breathing Exercise
Progressive Muscle Relaxation
Various Relaxation Techniques

Exercise and Diet

Exercise

Exercise can improve strength, fitness, mood and general wellbeing. But exercise isn't always straightforward when you are struggling with neurological fatigue and possibly other health issues.

The most important thing is to **do what works for you**.

Start by exercising in short sessions for three to five minutes a few times a day, rather than longer single sessions. Build up slowly, and monitor your body's response to exercise (you could re-visit the fatigue diary for this).

The easiest, cheapest form of exercise is **going for a walk**. The payback is huge, but pace yourself. If you haven't been for a walk for a while, set a realistic goal of five minutes, gradually increasing the time. Walking will help you to:

- maintain a healthy weight
- increase your energy levels
- prevent or manage various conditions, including heart disease, high blood pressure and type 2 diabetes
- strengthen your bones and muscles
- improve your mood
- improve your balance and coordination
- be happy.

Adapted from the Brain Injury Rehabilitation Workbook ByWilson, Winston and Bateman (2016)

Diet

There are changes that you may be able to make to your diet to improve your ability to manage your fatigue. If you think you could benefit from further information, refer to the Eating Well for Fatigue booklet.

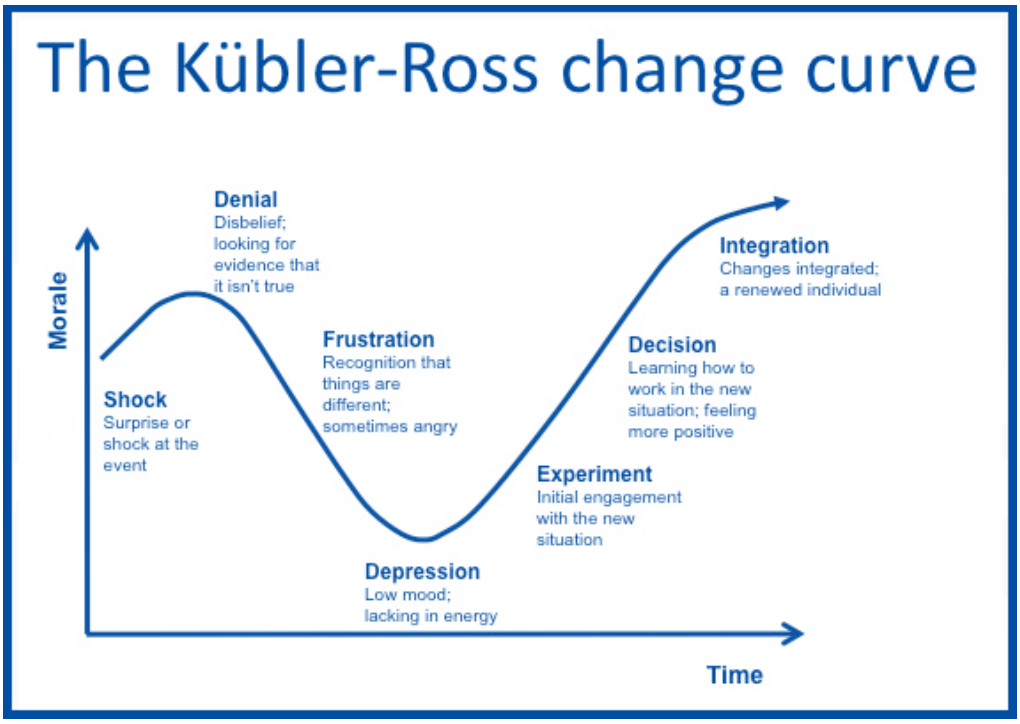
SUGGESTED HANDOUTS:

Eating Well for Fatigue

Change and Acceptance

We know that change is an inevitable part of life; but dealing with change when it is related to your health can be a very difficult thing to accept.

The Kubler-Ross Change Curve is a useful model to help us to understand change and the normal human emotions associated with it.



Acceptance means allowing the painful feelings and sensations to come and go as part of the natural process of loss, while dropping the struggle with them. By not getting caught up in them and being dragged back to the past, it becomes easier for your feelings to come and go without you getting 'stuck'.

Talking to your therapist or psychologist can help move through this cycle; as well as working on strategies to challenge negative thinking and increase positive action.

SUGGESTED HANDOUTS:

ANTs (Automatic Negative Thoughts)
How to Challenge ANTs

Goal setting for effective change

Changing your lifestyle can be a long-term challenge. A successful approach will need to take into account any barriers and consider our circumstances.

Setting goals can help us make changes to our lifestyles, e.g. managing fatigue, losing weight, being more active, etc.

Setting the right goal/s is an important first step.

Effective goals are:

S - ***Specific***
M - ***Measurable***
A - ***Achievable***
R - ***Relevant***
T - ***Time bound***

Make sure to **monitor your progress**. Success is a great motivator: as you see yourself getting closer to your overall goal, it will motivate you to continue to make changes. Using diaries (e.g. fatigue or sleep diaries) and goals to review your lifestyle regularly can help keep you on track and to reflect on your successes, as well as helping you to identify the next step.

….And when you succeed, remember to **reward yourself!**



Use the worksheet overleaf to help plan your goals.

SUGGESTED HANDOUTS:

Values worksheet

SMART Goal Worksheet

<table>
<tr><td colspan="2">What is the goal?

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