MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

How to manage fatigue

For people living with a muscle wasting and weakening condition

We have developed this information booklet in collaboration with people living with a muscle wasting and weakening condition and clinicians who specialise in muscle wasting and weakening conditions.

The aim of the booklet is to provide information to better support people to manage their fatigue. It's been developed with multiple conditions in mind and the advice is therefore general in nature. We recommend working through it with your healthcare team. Your occupational therapist, physiotherapist or neuromuscular care advisor will be able to support you in understanding all the different sections.

As it's quite a long document, you may choose to go through it one section at a time. The worksheets at the end are there to help increase your understanding and for you to include fatigue management into your daily life.

A special thank you to all the people living with a muscle wasting condition and weakening condition who helped us create this, and shared their thoughts on the impact of fatigue on their daily life.

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Content

Section 1:
Fatigue and muscle wasting conditions

Fatigue is a very common symptom when you live with a muscle wasting and weakening condition.

High levels of fatigue can have a big impact on your daily life. Activities such as walking, cooking or working can be limited.

Each person will have a different experience of fatigue and improving understanding of the causes of your fatigue can help you better manage your symptoms.

Although it's well recognised that many people with a condition experience fatigue, there are few studies in this area. The table to the right shows the frequency of fatigue experienced for a range of different conditions based on available evidence.

It's Important to remember that no two people are the same. Some people find fatigue to be their most difficult symptom, while others notice little change in their energy levels.

Condition	Fatigue frequency
Myotonic dystrophy	74-76%
CPEO	68%
CMT	64%
SMA3	64%
FSHD	61%
IBM	60%
Mitochondrial myopathies	60%
OPMD	54%
SMA1-2	34%

Section 1: What is fatigue?

Many people with a muscle wasting and weakening condition find it difficult to describe their fatigue. The type of fatigue you experience is different to the tiredness others feel after a busy day.

This section includes information about fatigue, which we hope will give you the tools to help describe your fatigue to others. It's difficult to provide one definition for fatigue. Although many people find the following descriptions helpful:

- An overwhelming sense of exhaustion and lack of energy, completely out of proportion to the activity being undertaken.
- Thinking of energy like a rechargeable battery, where the battery starts with less than a full charge and quickly runs flat.
- Thinking of energy like coins in a piggy bank or energy account, where each coin needs to be budgeted for an activity or task.

Fatigue is often related to a combination of factors. Although tasks that take more strength like walking uphill or carrying heavy bags can increase fatigue, other factors such as mood or diet can also affect your energy levels.

The following quotes are from people living with a muscle wasting and weakening condition describing how fatigue affects them:

My body feels very tired and heavy, usually after activity which wouldn't tire out most people, and my thinking can also feel sluggish.

Like living under a weighted blanket.

It feels like I'm driving with the handbrake on and no petrol in the tank.

Like carrying bags of sand around my legs.

I feel very tired, extremely weak and lack physical energy.

Worksheet 1 may help you to describe your fatigue

Take note

Although fatigue is a common symptom in muscle wasting and weakening conditions, it's important to remember a sudden change in energy levels can sometimes indicate you're unwell.

Acute, sudden onset fatigue can be a 'warning sign' from your body that something isn't quite right. If you notice a sudden change in your energy levels, contact your GP, care advisor or local neuromuscular team for advice.

Types of fatigue

There are two different types of fatigue – primary and secondary.

Primary fatigue	You experience this in your muscles and body due to your condition.
Secondary fatigue	This is not directly caused by your condition, but by factors which may be a consequence of living with a muscle wasting and weakening condition.

You can experience different types of fatigue - cognitive, physical, emotional or social. These types of fatigue can affect you in different ways.

Primary fatigue

You may experience muscular fatigue following exercise or repetitive tasks. This is related to muscle weakness caused by your condition.

Muscular endurance and physical stamina are limited in people with a muscle wasting and weakening condition. Your muscles may become tired more quickly than usual causing them to shake or cramp. You may experience muscle aches, or your muscles may start to give way or stop working. If you experience these symptoms, it could be a sign you've overdone it!

It's also important to remember your heart and breathing rely on muscles to function properly. Cardiac or heart, and respiratory or breathing problems, can also have a big impact on your energy levels.

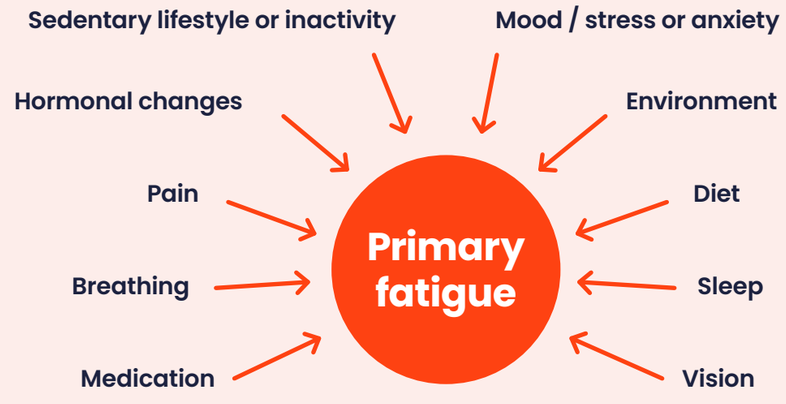
Some activities that can cause muscle fatigue include:

- Standing in the shower or at the kitchen counter
- Going up or down stairs
- Self-propelling your wheelchair outdoors
- Peeling/chopping vegetables
- Emptying the dishwasher
- Drying or styling your hair
- Typing on the computer
- Writing a letter by hand
- Unpacking the groceries
- Doing the housework
- Playing hide and seek with the kids

Secondary fatigue

There are many things besides muscle weakness that can contribute to feeling tired. These can include but are not limited to the factors in the image below.

To give an example, if you have problems with your vision, such as early cataracts, your eyes have to work much harder to help you to see clearly. The harder your eyes work, the more tired you'll feel. Your environment can also have a big impact such as temperature, noise and light levels.



Worksheet 2 in the appendix can help you think about which areas are most relevant for you

What might trigger my tiredness?

One of the most important steps in managing your fatigue is understanding and assessing the ways it affects you day-to-day.

Recording your activity levels for a brief period can help to identify patterns and triggers.

An activity diary allows you to regularly record your activities and fatigue levels throughout the day. Keeping a diary in this way can help you explore your energy levels. It can also help identify your fatigue patterns – what triggers or makes your fatigue worse, and what appears to reduce it.

On the next page is an example of an activity or fatigue diary. You can find a larger version in Worksheet 3 in the appendix.

If possible, keep the diary for between three to seven days in a row. If you work or have major differences between days, keep the diary for at least one or two days while working, and for one or two days when you are not working.

	Wake up time	Morning	Afternoon	Evening	Sleep time	Comment about sleep
Monday						
Fatigue rating						
Tuesday						
Fatigue rating						
Wednesday						
Fatigue rating						
Thursday						
Fatigue rating						
Friday						
Fatigue rating						
Saturday						
Fatigue rating						
Saturday						
Fatigue rating						

Key points:

- Fatigue is common for people with muscle wasting and weakening conditions.
- It can be unpredictable and impacts on what you're able to do each day.
- Fatigue can be difficult to explain to others.
- Many factors impact on fatigue, not just muscle weakness.
- Using a diary to analyse your fatigue is a good starting point.

Section 2:

Mood and fatigue

Our mood and fatigue are closely related and have an impact on each other. A low mood can make you feel particularly lethargic, and demotivated. Feeling tired can also make you feel low.

There are many overlapping symptoms when considering low mood and fatigue, which can include:

- Difficulty getting out of bed in the morning
- Poor appetite
- Difficulty initiating or completing tasks
- Lack of motivation
- Socially withdrawing
- 'Brain fog' or becoming forgetful

Take note

You may experience some of these symptoms due to your fatigue only, and it may not mean that you have a problem with your mood.

Our mental health is just as important as our physical health and deserves the same attention and appropriate help if needed.

If you're feeling particularly low, or if your fatigue is made worse by a low mood, it's important to discuss this with your GP. You can also self-refer to a local talking therapies team in most areas. This is sometimes called the Wellbeing Service or IAPT service (IAPT stands for Improving Access for Psychological Therapies).

Unhelpful thoughts:

The way we think about ourselves and our fatigue can have a big impact on the way we feel. Challenging negative thought patterns in relation to fatigue can be very helpful.
Below are some examples of unhelpful, negative thoughts related to fatigue:

- I am lazy
- This fatigue means my condition is taking over my life
- I have no control
- I am useless because I can't do all the things I used to do
- I am making too big a deal over this - everyone gets tired and they keep going
- Others must think I'm lazy
- I have to keep going regardless, so that I'm not a burden on others
- I must push through and finish tasks in one go
- I'd better do very little in case it makes my fatigue worse
- I must do this now, even though I'll really suffer for it later, because I might not be able to do it in the future

It's important we challenge these negative thoughts as they are untrue and can impact our mood.

You may start to challenge your thoughts by asking yourself a few simple questions such as:

- What evidence is there that supports/ disproves these negative thoughts?
- What would you say to a friend in the same situation?

Worksheet 4 in the appendix is a thought diary which can help you identify and challenge these thoughts that may arise in different situations. We would advise you to speak to someone in your medical team if you're struggling with this.

Further information:

Mental health charities
https://hubofhope.co.uk

Mental health support on our website

www.musculardystrophyuk.org/support/information/your-condition/mental-health/

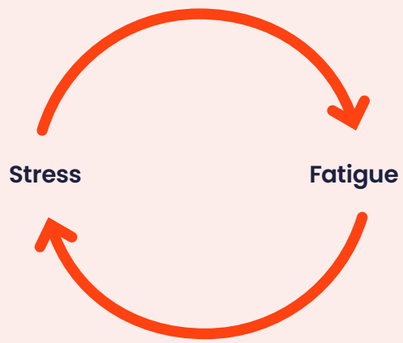
Stress and fatigue

Many people living with a muscle wasting and weakening condition can find that stress seems to make their symptoms worse. Others find stress doesn't have much impact. In the same way that fatigue affects people with muscle wasting conditions differently, it seems the impact of stress varies between people as well.

When we're stressed, we need more energy to think, problem solve and deal with everyday situations. For example, we may be less patient with someone if we've not slept well. It might also be harder to be patient when faced with a child's temper tantrum at the end of a difficult day.

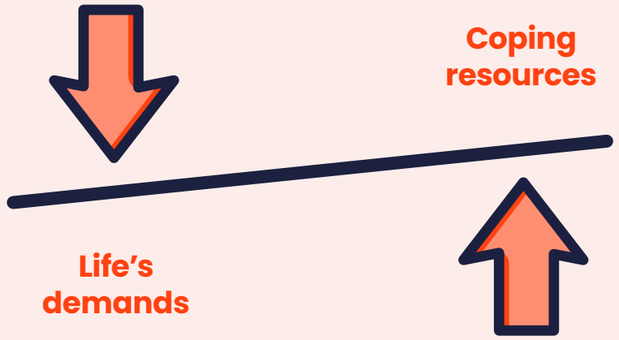
At times of stress, symptoms may feel stronger because your energy reserves have been drained. As people living with a muscle wasting condition experiencing fatigue have less energy available in their 'energy bank', stress can make life's daily challenges and symptoms harder to deal with.

Dealing with a long-term muscle wasting condition is stressful. The unpredictable, often overwhelming and invisible nature of fatigue can add to the stress. A cycle can be created, with fatigue causing stress and stress increasing fatigue levels.



We can think of our life in terms of a seesaw: when resources in our life outweigh demands this could lead to boredom.

However, when demands outweigh resources this can lead to stress. For healthy living, ideally we want a balance between demands and our resources to deal with those demands.



While it's not realistic to remove all stress from our lives, it is possible to learn how to reduce its negative impact so it can work for rather than against us.

It's important to learn to recognise when you're feeling stressed. It may be helpful to think about the daily events or concerns you find most stressful. **You could make a list of:**

- The things that have caused you the most stress in the last two weeks.
- Positive experiences that were mentally or physically refreshing or calming.

Some examples of situations that may trigger your stress:

- Work pressure
- Attending hospital appointments
- Ill health (you or someone close to you)
- Frustration at not being able to do certain things you used to
- Travelling
- Attending social events

Key points:

- Fatigue is impacted by our mental health.
- A low mood and high stress can make fatigue worse.
- Doing enjoyable things to boost your mood and combat stress can have a positive impact on your fatigue.
- Learning to balance life's demands with a muscle wasting and weakening condition can be stressful. Be kind to yourself and take time to adjust to things.

Take note

Seek advice and support from your GP if you have concerns about low mood or anxiety.

Tips to help manage stress and boost your mood

- **Eat a healthy, balanced diet** and have regular meal times.
- **Optimise sleep,** have a set routine where you get up and go to bed at a regular time each day.
- **Get dressed and ready for the day** even if you're not planning on going out. This is very important.
- **Plan to do something enjoyable** each day, this should be something that brings you pleasure and you want to do, not something you feel obliged to do. Prioritise doing this without feeling guilty.
- **Keep in touch with friends and family.** If you can, spend time having positive social interactions with family and friends.
- **Try to get out of the house** a few times each week for a change of scene. This could just be to your local park or high street for some window shopping.
- **Reframe the situation** - think about the things you can control (your thoughts and your response) rather than the things you can't (how other people behave or respond).
- **Try different relaxation techniques** such as mindfulness and meditation. There are lots of useful apps and websites which can support you with this such as Headspace and Calm.
- **Laughter is a great stress reliever** - in fact we often laugh the hardest when we have been feeling most tense. Laughter triggers 'feel-good' hormones and boosts the immune system.
- **Adjust your expectations.** Are your expectations unrealistically high? Try not to expect too much of yourself or others. Nobody's perfect!
- **Try to avoid situations that cause you the most stress.** This is not always possible, but doing things such as leaving early to reduce the need to rush can be helpful.
- **Keep as active as you can.**
- **Try to engage in a regular form of exercise.** This could be a walk around the garden, or chair-based yoga or pilates. Choose something you enjoy and that feels manageable, even just a little exercise can go a long way to improving how you feel.

Further information and helpful resources:

- **NHS well-being website**
  www.nhs.uk/every-mind-matters
- **NHS website with free tools and resources to improve your mental health**
  www.nhs.uk/mental-health/self-help/guides-tools-and-activities
- **Mindfulness tips**
  www.mind.org.uk/information-support/drugs-and-treatments/mindfulness/mindfulness-exercises-tips/
- **Stress Management Society**
  www.stress.org.uk
- **NHS stress management advice**
  www.nhs.uk/every-mind-matters/mental-health-issues/stress/
- **Exercise**
  www.musculardystrophyuk.org/exercise-with-condition

Section 3:
Problems with sleep

Good quality sleep is a good way to help improve your energy levels.

Sleep problems are common in people with muscle wasting and weakening conditions. Some people may have difficulty falling asleep, or may wake in the night and have trouble getting back to sleep. People may have restless, light sleep and may find themselves sleeping in the day or getting up much later than usual.

It's important to remember that while fatigue and sleep impact on one another, they are two separate things. You can have problems with sleep or problems with fatigue, or both.

While a lack of sleep can be very frustrating and can have a significant impact on your function and quality of life, it's important to remember it will not cause your body harm.

The quality of your sleep can be affected by having too much, as well as too little sleep. The effects of poor-quality sleep can include the following:

- A loss of energy; lethargy
- Lowered immune functioning
- Increased feelings of low mood, anxiety, irritability
- Reduced tolerance to pain and other symptoms
- Poor memory and concentration
- Decreased motivation

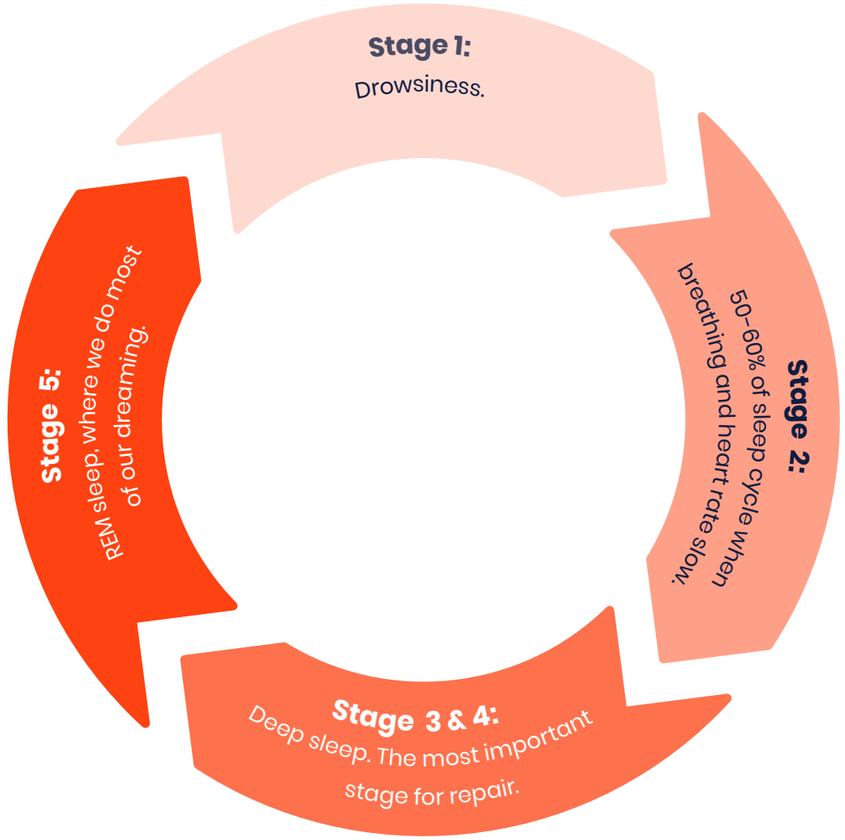
How much sleep do we need?

The amount of sleep we need varies from person to person. Some people only need four or five hours sleep, while others may need eight or more.

The amount of sleep needed also varies across our lifespan. Newborn babies spend about 16 to 17 hours asleep, while people in their 70s may need fewer than six hours of sleep. Achieving restful sleep that is relatively undisturbed is the most important thing.

Stages of sleep

Sleep occurs in repeat cycles of approximately 90 minutes, with brief periods of wakefulness in between that we often don't remember.



If you're lying in bed worrying you can't fall asleep, try to remember a lack of sleep will not harm or damage your body. Our bodies are very clever and will recoup missed sleep, particularly the deep sleep and REM stages, at the earliest opportunities.

Normal sleep drivers

Circadian rhythms

The term circadian comes from the Latin 'circa' meaning 'about' and 'dies' meaning 'a day'. Circadian rhythm therefore means 'a rhythm lasting about a day'.

Circadian rhythms are like an internal clock controlled by the brain, based on a cycle of approximately 24 hours.

Our circadian rhythms are affected by external cues, such as daylight, the different seasons, social activities, and the timing of meals.

Circadian rhythms can be disrupted by travelling across time zones (jet lag), working shifts and sleeping for long periods during the day. An irregular sleep pattern can also disrupt our internal clock or body clock.

Understanding sleep

The longer we're awake the sleepier we usually become. Extended wakefulness increases the body's drive for sleep.

We build up an increasing sleep debt with each hour we spend awake. After a good night's sleep, this debt is paid in full - the person wakes feeling refreshed and back 'in balance' the next morning.

The drive for sleep is naturally stronger when we first go to bed than later. This is why a nap can make us feel better. Naps can reduce the body's drive for sleep at night time, and should be avoided if you have sleep difficulties.

If you stop or reduce naps, remember that it's normal to feel more tired at first. As the quality of your night-time sleep improves over time, you will adjust and may find that you need less sleep in the day.

If you find it difficult to go without a day time nap, try to take one early in the afternoon to minimise the impact on your night-time sleep.

Factors that may affect sleep quality can be divided into five main types:

Environment	Physical	Emotions	Thoughts	Behaviours
Temperature	Interrupted sleep due to bladder difficulties	Anxiety	Worrying about the next day	Drinking alcohol just before bed
Noise levels	Difficulty getting comfortable due to pain	Depression	"Oh no, I'm never going to fall asleep, and I've got that really important meeting tomorrow"	Working on a screen just before bed
Mattress	Effects of alcohol or caffeine	Over-excited		Eating late at night
Lighting				

Take note

If medical issues are affecting your sleep, speak to your GP or consultant for advice and support.

Tips to improve your sleep

Associating your bed with sleep

As humans we're very good at making associations, often at a very subconscious level.

Repeated nights of poor sleep can cause the bedroom to become associated with negative emotions and with being awake. Using our beds and bedrooms for waking activities including watching TV, chatting on the phone or surfing the internet during the day can also be unhelpful.

Try to keep your bed as a place for sleeping, not using your phone, TV, work or calls. This will reinforce the more helpful association between your bed and sleep. With time, your bed will become a place you associate with sleep.

Establish a sleep/wake routine

Get up at the same time each day, seven days a week. This is important for supporting your circadian rhythm and kick starting your sleep drive.

If you like to lie in at the weekend, try to get up no more than 15 minutes later than usual. If you start to get up at roughly the same time each day, you will find you begin to feel sleepy at a particular time of the evening.

wake up regularly in the night, try going to bed 15 minutes later each week. This should help you to fall asleep more quickly and wake less during the night, by increasing your drive to sleep at night.

Keep to a bedtime routine

Not having a separation between day and night time activities can mean we bring our worries and stresses from, the day into the night.

Instead, try to create a time where you can process the events of the day. This can include a period of relaxation at least an hour before bed, and should help you achieve good quality sleep at night.

Get used to doing the same things every night before you go to bed like taking a bath, drinking a milky drink, reading a book or listening to relaxing music.

Sticking to a clear routine each night will act

Do...

- **Practice a relaxation technique** such as soft stomach breathing or visualisation during the daytime (see worksheet 5 in Appendix). This can also be used as a tool to help you get to sleep at night time.
- **Keep active** in the day as this can improve sleep. Avoid strenuous exercise within four hours of bedtime as it can interfere with sleep.
- **Try having a warm bath or shower** an hour before bed (cooling down after a bath can trigger sleep hormones).
- **Turn down any blue light** on your electronic devices if possible.
- **Start your bedtime routine by writing down any worries** which come to mind, and make an action plan for the next day.
- **Reduce daytime naps** (gradually) if they are disrupting night-time sleep.
- **Make your bed and bedroom as comfortable as possible** (e.g. lighting, noise, temperature, etc.).

Try to avoid...

- **Going to bed when you don't feel sleepy.**
- **Napping,** especially in the evening or late afternoon.
- **Playing 'catch-up'** and staying in bed to recoup sleep as this will disrupt your body clock.
- **Drinking tea, coffee, fizzy drinks in the evenings** (ideally avoid caffeine after 14:00).
- **Drinking more than a couple of units of alcohol** near to bedtime.
- **Eating large meals** (especially spicy/fatty foods) before bedtime. If you are hungry, have a light snack instead.
- **Doing anything mentally or physically taxing before going to bed** (e.g. work, study, dwelling on thoughts, worries, decisions).
- **Exercising close to bedtime** (as it releases stimulants that make it difficult to wind down).

Below are examples that other people have tried to help support their sleep

If sleep eludes you...

- Remember that a lack of sleep will not harm or damage your body.
- Jot down your thoughts or worries if they are getting in the way of sleep.
- Try a relaxation technique, such as deep breathing or visualisation.
- Try focusing on keeping your eyes open... yes, open! Strange as it sounds, this seems to promote the urge to close them.
- Try a repetitive mental exercise, such as thinking of countries starting with each letter of the alphabet, or repeating a simple phrase
- If you are not asleep within about 15 minutes, get up, get out of the bedroom, go to a waking space and do something relaxing and enjoyable. For example, listen to relaxing music or read. Return to bed when you feel sleepy. If you are not asleep within a further 15 minutes, repeat this process.
- If getting in and out of bed is too difficult, then consider other ways of adapting the environment to achieve a waking space and sleep space in bed. For example: try sitting up, turn the light on, changing or removing your duvet/blanket or sitting on the other side of the bed. Once you feel sleepy, then return to your original sleep position and turn out the light.

Further information:

- **Sleepio**
  https://www.sleepio.com/sleepio/nhs/391#1/1
- **www.sleepstation.org.uk**

Worksheets 5 and 6 in the appendix can be used to help with your sleep.

Key points:

- Fatigue and sleep are separate problems but impact each other.
- Our thoughts and emotions can negatively impact on our sleep.
- Having a regular bedtime routine can help improve your sleep.
- Try avoid doing daytime activities in bed such as work, reading emails or taking calls.
- Mindfulness and breathing exercises can help you fall asleep.
- Coffee, tea, energy drinks and alcohol can have a detrimental effect on sleep and fatigue.

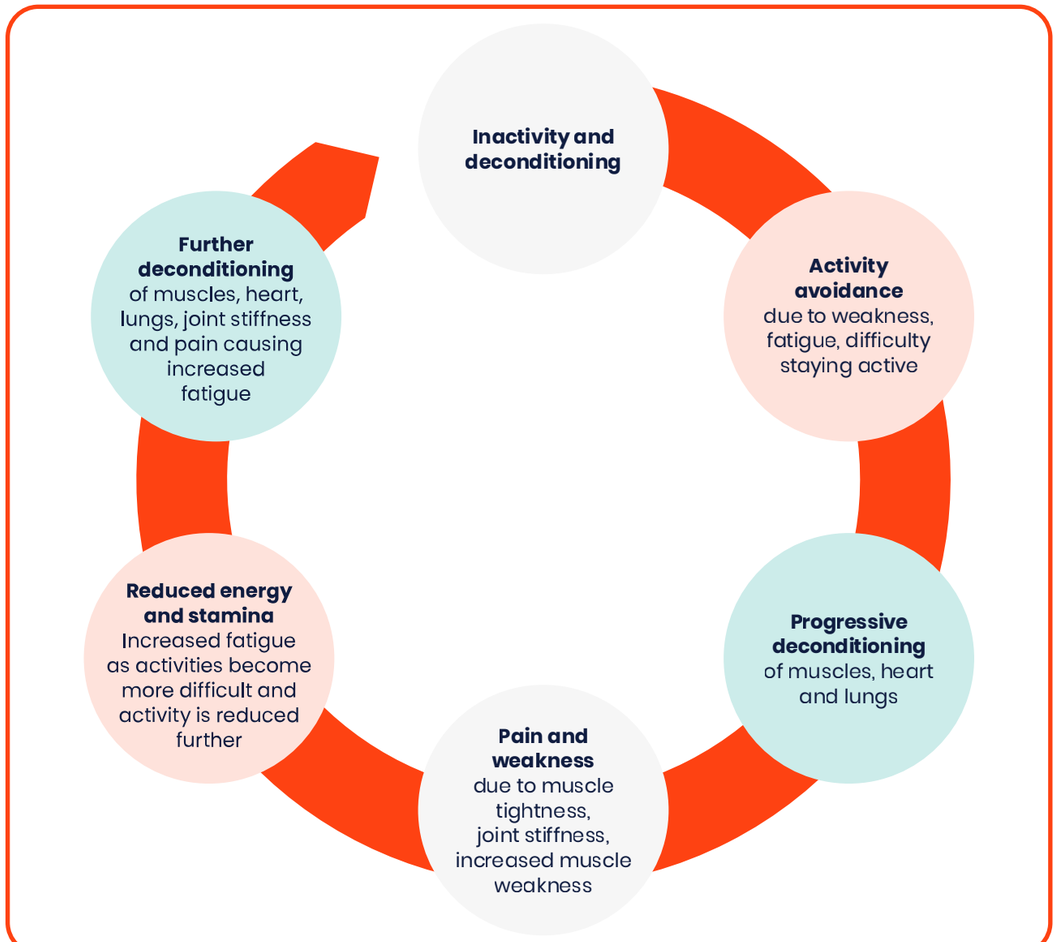
Section 4:
The importance of exercise and activity

What is activity/exercise? Why is it important?

Activity is the quality or state of being active.

Exercise is defined as physical activity that is planned, structured and repetitive, aimed at conditioning any part of the body, improving health and maintaining fitness.

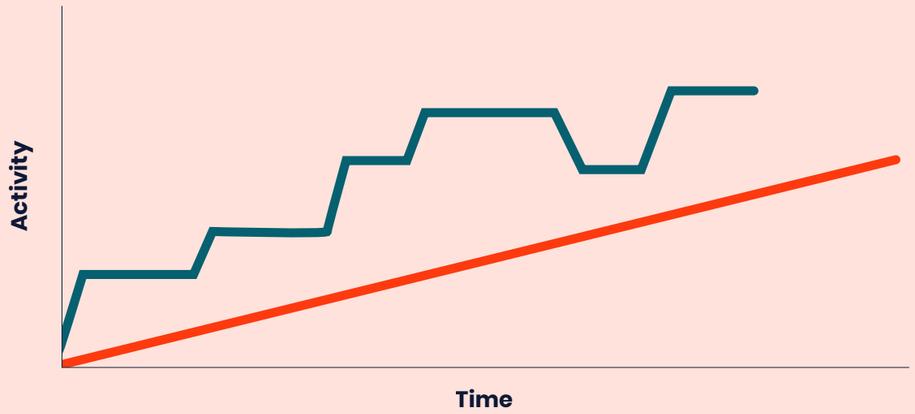
Many people with a muscle wasting and weakening condition are nervous about getting active or exercising, due to fear that it may increase fatigue. However, inactivity can lead to deconditioning and worsen fatigue.



It is important to break this cycle of inactivity by introducing activities gradually. However, people can go from doing nothing to doing lots and then needing to rest for days to recover. This is called the 'boom-bust' activity cycle. We discuss this in more detail on page 34.

Planning small amounts of activity and balancing this with rest will help you to very gradually increase what you are able to do. This may take weeks or months but can help you to optimise your activity levels without negatively impacting on your fatigue in the long run.
The graph below demonstrates how this may look.

Step-wise approach to slowly increasing activity levels



This graded approach, can help your body gradually adapt to doing more, and will mean you don't need to rest for extended periods to recover from activity.

How do you know how active you are?

Living with a long-term neuromuscular condition day-to-day can make it challenging to identify how active you are and to balance activity with fatigue.

The first step is to quantify how active you are, and to score how fatigued you feel. Keeping an **activity and fatigue diary** for a couple of weeks, can help you identify patterns and give you ideas on how to interrupt the cycle of inactivity to optimise conditioning.

See worksheet 3 in Appendix

Tips to remember:

- Maintain activity - little and often
- Avoid long periods of inactivity
- Day to day household chores are classified as activity
- Activities of daily living (e.g. getting washed and dressed) are also classified as activity
- Plan rest periods into your day/week to manage activity and fatigue
- Consistency is key

How to get and stay active?

- Use **activity monitors** or step counters on your phone or smart watch, to help keep a track of your activity throughout the day.
- It may be helpful to **record step counts** for two weeks, to identify the least active day. Try to **gradually increase steps** on these days (even if by 5 or 10 steps) working towards a consistent number of steps each day of the week.
- Try to **avoid sitting still for more than 30 minutes**, even if you just stretch or stand and take some steps a few times an hour.
- If you are unable to stand, consider **chair-based exercises or stretches** focusing on your posture, arm and head movements.
- If you haven't done any regular activity or exercise for a while, **start slowly and gradually build up.** Consider doing an activity you know you can achieve, e.g., a walk to the shops or self-propelling down the road, then build up the activity by increasing your speed or taking less breaks whilst going the same distance.
- Add or increase your activity once you can **comfortably and consistently** complete what you are doing for few weeks.
- The **type of physical activity** and/or exercise most appropriate for you will **vary from person to person.**
- Try to **find something you enjoy** that you can safely and easily achieve and can fit in to your routine. This will depend on your own specific needs, interests and circumstances.
- If you can, try to **exercise with peers** (even if this is virtually) or tell people what your plans for exercise are – this can help to keeping you on track with exercise.
- Try and **work towards a goal,** for example:
  - avoid sitting more than 30 minutes without moving, or
  - do some regular exercise/activity three times a week.
- **Keep a record** of what exercise and activity you do and when, so that you can reflect on gains and improvements.
- It is possible to introduce strength training or aerobic exercise to your schedule. However, this should only be introduced if you are able to **maintain regular activity,** maintain activities of daily living, manage activities that are important to you and manage fatigue effectively.

Further information:

- **We have produced exercise guidelines in collaboration with specialist neuromuscular physiotherapists. You can find out more information on our website:**

  www.musculardystrophyuk.org/support/information/your-condition/exercise/

Key points:

- Activity or exercise can have a positive impact on fatigue.
- Day-to-day tasks such was cleaning, gardening or getting dressed all contribute to your activity levels.
- Try to break the vicious cycle of inactivity by slowly increasing what you do.
- Find an exercise or activity that you enjoy – this could be at a local gym, outside in the park or at home following a video.

Section 5:
The relationship between breathing and fatigue

The respiratory system takes oxygen from the air we breathe. This oxygen is combined with sugars from the food we eat to make energy. Carbon dioxide is a waste product of this process. If we don't remove this carbon dioxide efficiently, we can experience several different effects, including fatigue.

People with muscle wasting and weakening conditions can have difficulty breathing deeply enough during sleep. This is called sleep related hypoventilation and is caused by weakness of the respiratory muscles, which affects the efficiency of gas exchange between the alveoli (air sacs) and the blood.

Fatigue and/or daytime sleepiness are well recognised in a wide range of sleep-related breathing disorders, not just those associated with muscle weakness.

Fatigue, morning headaches and/or daytime sleepiness are symptoms of sleep related hypoventilation Other symptoms of sleep related hypoventilation include onset of vivid dreams, perhaps even nightmares, and a change in some blood test results or the Epworth Sleepiness Scale score.

The diagram below summarises the relationship between breathing and fatigue

1

Underlying muscle weakness
- Weakness of respiratory muscles
- Difficulty taking deep breaths
- Limits thoracic cage mobile

2

Impact on gas exchange
- Reduction in breathing in oxygen
- Limited blowing off CO_2
- Leading to headaches and daytime sleepiness
- Reduced appetite

3

Fatigue
- Feeling fatigued
- Daytime lethargy
- Reduced activity levels

Take note

Please talk to your GP or neuromuscular team if you experience any of the signs or symptoms discussed in this section and are not under the care of a respiratory service.

Regular and effective monitoring of breathing and blood gas levels is important for people with respiratory problems. This can help to identify treatments to help maintain respiratory efficiency, which include:

- Breathing exercises
- Positioning (in terms of sitting and/or when lying in bed)
- Non-invasive ventilatory support (NIV), such as BiPAP or CPAP
- Invasive ventilatory support, such as via a tracheostomy

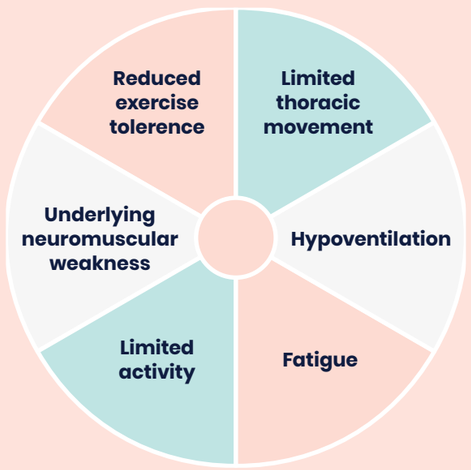
Respiratory muscle weakness is not a feature of all neuromuscular conditions. People with conditions where respiratory muscles are known to be affected may not always have clear signs or symptoms in the early stages. As there are so many factors involved in fatigue, in the early stages of sleep related hypoventilation it might not be obvious that respiratory effort is indeed a contributory factor to fatigue.

It is important to note that other sleep related breathing disorders may also need to be considered, especially for those not expected to have respiratory muscle weakness. The most common sleep related breathing disorder in the general population is obstructive airway sleep apnoea. This can be caused by excessive snoring, having a high body mass index (BMI) or even enlarged tonsils. The physical effects of obstructive sleep apnoea can present in exactly the same way as sleep related hypoventilation caused by neuromuscular weakness, including daytime sleepiness and fatigue, and can be assessed and managed in similar ways.

Unfortunately, the method of delivering NIV support itself can have a negative impact on sleep quality/quantity, which might add to fatigue by disrupting sleep. The requirements of wearing a mask over the mouth and/or nose throughout the night, can take a long time to get used to. Many people simply find it creates more disruption to their comfort and sleep than they can tolerate.

If you cannot tolerate NIV, you should speak with your respiratory team ASAP to ask about alternative options for different types of masks. Not using NIV that has been recommended risks serious health problems in addition to the impact this will have on levels of fatigue.

Factors impacting on fatigue and respiratory function



Before NIV I was really struggling to function due to fatigue. I started using it for short periods at a time, tried a few different masks to find best fit.

Activities that include an element of breathing control, may be of benefit for reducing fatigue:

- Meditation
- Tai Chi
- Qigong
- Yoga
- Pilates

These activities are frequently recommended as complimentary therapies for long-term conditions such as multiple sclerosis, chronic fatigue syndrome or ME, and those undergoing cancer treatments.

There is very little evidence of the benefit of these activities for fatigue in neuromuscular conditions but this is likely due to the fact it has not been widely investigated, rather than studies showing it is not effective.

Breathing exercises

There is evidence that breathing exercises can have a direct impact on fatigue in some health conditions. These exercises work in similar ways to NIV in that a deeper breath in (inhalation) is followed by larger breath out (exhalation), increasing the amount of carbon dioxide removed from the blood as it passes through the lungs.

Reducing carbon dioxide may help increase levels of alertness when awake and gives a reduced sensation of fatigue.

One theory of why we yawn when tired is that it forces a larger volume of air in and then out of the lungs specifically to remove carbon dioxide and reduce the feeling of sleepiness and make us more alert.

Using breathing exercises in the daytime may help to improve respiratory efficiency when awake, but will not be a substitute for NIV requirements if sleep related hypoventilation has been identified.

Some people will find that as their muscle weakness progresses, they may need to use NIV support for periods during the day to maintain their energy levels and health.

Try worksheet 5 in the appendix for a breathing exercise.

I regularly try to take deep breaths and this gives me a temporary energy boost, I use a cough assist device twice a day and this also can have a positive effect on fatigue, but it can also be physically tiring.

Key points:

- Respiratory muscle weakness can add to fatigue by reducing the ability to remove carbon dioxide from the blood during breathing.
- Sleep related hypoventilation may be subtle in the early stages, so its impact on fatigue may not be appreciated.
- NIV use can help reduce fatigue by improving the removal of carbon dioxide and improving sleep quality/quantity.
- Other causes of sleep related breathing disorders may need to be considered in the absence of respiratory muscle weakness.
- Targeted breathing exercises or related activities may help with fatigue.

Section 6:

The role of diet in fatigue

Getting sufficient nutrition can be a challenge for people with a neuromuscular condition. Many have difficulty chewing and swallowing, or feel fatigue at levels that reduce appetite and make eating a chore. Limited caloric intake can break down muscles faster, possibly speeding disease progression.

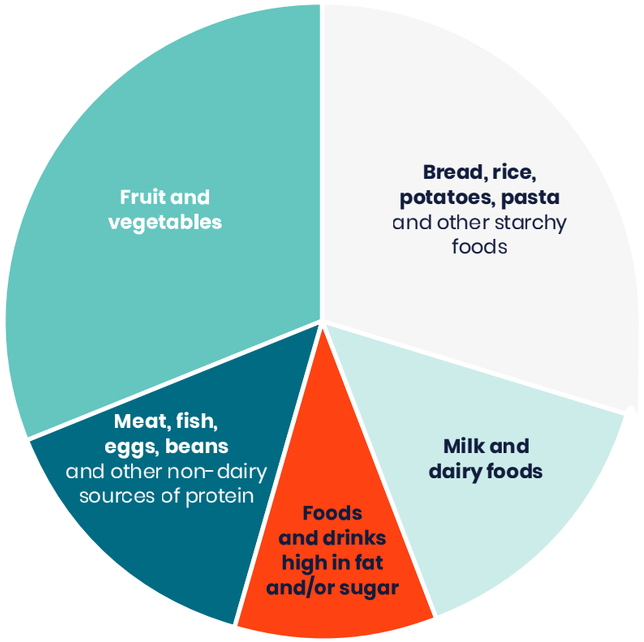
What you eat can have an impact on your levels of fatigue. For example, large, hot meals can sometimes make fatigue worse and caffeine or sugary snacks might have an initial 'pick-me-up' effect, but leave you feeling more tired later.

Some people with bladder problems or reduced mobility might drink less to reduce their need to go to the toilet. Not drinking enough water can lead to dehydration, which can cause fatigue.

Many people with neuromuscular conditions struggle with constipation due to weak stomach muscles and limited mobility, therefore many dietitians recommend a diet high in fibre.

What is a balanced diet?

This diagram demonstrates the general dietary advice provided by the NHS, but you may need a bespoke diet from a trained dietitian. You can discuss this with your clinical team if you have any concerns.



Further information:

More information about healthy, balanced eating can be found on the NHS Eatwell guide: www.nhs.uk/live-well/eat-well/food-guidelines-and-food-labels/the-eatwell-guide

Importance of a healthy weight

Maintaining a healthy BMI is important. If your BMI is too high (overweight) your body needs to work harder to move around. If your BMI is too low (underweight), this can impact on the strength of your muscles. The extra effort needed to move around contributes to your fatigue.

BMI is calculated by:
weight (in kg) divided by your height (in m2)

Check your BMI here:
https://www.nhs.uk/health-assessment-tools/calculate-your-body-mass-index/

BMI (kg/m2)	Class
< 15	Severely underweight
15 - 18.5	Underweight
18.5 - 24.9	Healthy weight
25 – 29.9	Overweight
> 30	Obese

Involvement of health care professionals

Speech and language therapists may be able to work with you to improve the strength and range of motion in muscles that control chewing and swallowing. They may also be able to teach safer approaches to swallowing to lessen the risk of choking.

Dietitians can help in creating an appropriate meal plan so you get the nutrition you need in ways easy to eat and swallow. This might mean substituting a meal-replacement shake for solid foods, or turning to softer foods.

Occupational therapists can help with advice on equipment to aid eating such as adapted cutlery or specialist feeding aids such as a Neater Eater.

Meal time tips for managing fatigue:

- Do not rush a meal, rushing increases the risk of choking.
- Avoid dry foods with loose crumbs, like day-old bread, crackers, or chips if these cause you to cough.
- Taking small bites may make chewing and swallowing easier.
- Minimise distractions during mealtimes, like radio or TV, to concentrate on the meal and reduce the risk of choking.
- Sitting in an upright position can help with swallowing.
- Eat smaller meals more frequently.
- Consider the timing of meals and when they best fit your sleep pattern or medications you take.
- Often food such as tinned and frozen is as healthy for you as fresh and easier to prepare.
- Cooking in bulk and using leftovers or freezing portions can help you to maintain a balanced diet.
- Preparing food prior to cooking, such as chopping vegetables or getting all the ingredients ready, can help to split up tasks and limit fatigue.

Eating regular small meals during the day helps me manage my energy levels

Medication related to eating

Excess saliva is common in patients with weakened tongue and throat muscles, but certain medications can be used to lessen saliva production.

A side effect of steroids is that it can increase your appetite leading to weight gain, which can lead to greater fatigue levels, as you have a higher energy expenditure to move excess weight.

Additional vitamin or food supplements can be beneficial, but should be discussed with your clinical team. Refer to supplement section for more information.

Tube feeding

In some specific cases, clinical teams may recommend a feeding tube for nutritional support.

This can be called a PEG or a RIG. This is a tube surgically connected directly to the stomach, bypassing the mouth and oesophagus to ensure that people are getting sufficient nutrients. If a person is unable to get the nutrients they require through oral feeding, a feeding tube can help to improve their energy levels.

Key points:

- A healthy, balanced diet should be followed to help combat fatigue.
- Dehydration contributes significantly towards fatigue.
- Your BMI can impact on your mobility and energy levels.
- Preparing food in advance or using tinned, frozen or pre-cut food can be helpful.
- If mealtimes make you tired, eat smaller meals more regularly.

Section 7:

Medication and supplements for managing fatigue

It is important to understand the difference between fatigue and fatigable muscle weakness when considering management with medication.

Fatigue has been discussed in detail within this document. This is different from fatigable muscle weakness, where muscle strength reduces with repetitive use. Fatigable muscle weakness, caused by a fault at the neuromuscular junction, is seen in conditions such as myasthenia gravis. This can be treated effectively with medication, such as steroids or pyridostigmine. Muscle weakness caused by changes in potassium levels, seen in some types of conditions called channelopathies, can also be treated with medication.
Some people with mitochondrial disease can experience fatigue, due to problems with energy production within their cells, and may find a food supplement called Co-enzyme Q10 helpful. People with myotonic dystrophy can sometimes experience excessive daytime sleepiness, which can be treated with specific medications.

For other types of fatigue, there is little evidence that medication (either prescription or over the counter) is an effective treatment. There is no recognised drug therapy for conditions such as ME or chronic fatigue syndrome (CFS), where fatigue is the main symptom.

Medication for pain and mood

Medication prescribed for pain and mood, rather than for fatigue or weakness, may have an impact on fatigue levels. Pain medication may help to improve sleep and reduce pain, which can in turn help you to increase physical activity. Some medications used for pain relief in muscle wasting and weakening conditions may also have mild anti-depression effects - with improved mood, physical activity levels may increase.

Side effects of medication

Some medications can cause drowsiness. It may be helpful to discuss your medication with your GP or pharmacist. Sometimes changing the time of day you take certain medications can have an impact on fatigue. Medications for pain, mood or cramps may contribute to drowsiness.

Take note

It is important to take all medication as prescribed and recommended by your doctors. Do not make any changes to your prescribed medication without first discussing with your GP or specialist.

Vitamins and supplements

There are many over the counter products (vitamins, caffeine products, herbal remedies, etc.) marketed with claims of helping to reduce fatigue and boost energy levels. Supplements like these, have little regulation in terms of testing for efficacy and safety. Whilst there are no concerns that such supplements cause any additional harm in muscle wasting and weakening conditions, there is also no reliable and robust research to show they have any more benefit than a well-balanced and healthy diet. Caution should be taken when considering supplements or energy drinks that contain high levels of caffeine.

Anyone with a diagnosed vitamin or mineral deficiency (based on blood test results) should take an appropriate dose of the required supplement as prescribed/recommended by a doctor.

Vitamin D

Unlike other vitamins and supplements, there is good evidence of the benefit of vitamin D. This is needed to maintain adequate bone health, which is particularly important if you are prone to falling. It also has other important roles within the body. Low levels of Vitamin D in the body can cause fatigue.

We naturally use sunlight to make Vitamin D in our bodies, and so people living in places such as the United Kingdom may benefit from Vitamin D supplements, especially in the winter.

You should speak with your GP if you would like your vitamin D levels checked. Your GP, pharmacist or clinical team can advise on current NHS guidelines for vitamin D supplementation.

Key points:

- General fatigue cannot be treated with medication.
- Some medications can cause drowsiness as a side effect.
- A small number of muscle wasting and weakening conditions have medications that can help treat specific causes of fatigue and fatigable muscle weakness.
- Over the counter supplements and vitamins are unlikely to do any harm, but it's not clear they are any more effective than a healthy and balanced diet.
- Vitamin deficiencies identified with blood tests should be addressed by GP or specialist service.
- Daily vitamin D supplements may be helpful for people living in the UK, especially in winter months where daylight is limited. Your GP or pharmacist can advise further.

Section 8:
Strategies for managing fatigue

By now you should have a good understanding of some of the things that influence your fatigue. This section focuses on practical ways to help you better manage your energy levels.

Unfortunately, there is no quick-fix for this symptom. Fatigue management is about learning how to live with your fatigue and adjusting your lifestyle to help you cope better.

Energy conservation techniques

Having a good understanding of your own fatigue is the first step to being able to manage your energy levels.

The amount of energy you use, and speed that you use this energy, will vary between activities and tasks. It's important that you do not avoid activity, but instead use energy conservation techniques. These techniques help to adapt how you do things to save energy, so you do not feel as fatigued. Conserving energy in this way will allow you to continue with everyday essential tasks as well as activities you enjoy.

1.

Many people use analogies to help them understand how to manage their energy levels. We introduced some helpful descriptions at the beginning of this guide, and look at them in more detail below: Think about your energy levels as a battery. When you complete an activity your battery level will become lower. Using rest, you may be able to recharge your battery to avoid your energy level depleting. Some activities will drain your battery more quickly than others. Sometimes, even after a good night's sleep, your battery may not fully recharge.

2.

Think about your energy levels as an 'energy bank'. When you complete any activity, you are withdrawing energy from your bank. You have a finite amount of energy in this bank each day, and you cannot continue with activity once all the energy has been used. When you rest you are depositing energy back into your energy bank. We have suggested some strategies over the next few pages to help you manage your energy levels better. This is to allow you to continue with activities that are important to you.

Prioritisation

Taking time to re-evaluate which activities are most important and what can be adapted, is essential to managing fatigue.

It's important to prioritise activities that must be done, as well as activities you enjoy doing. Can you complete these activities at the time of day when your energy is higher?

Is there anything you can stop even if for a short time or avoid something that is non-essential? Are there tasks you could delegate to family, friends or employed support?

Sometimes writing out your priorities for the week can help you to decide what needs to be done. **Below are some examples of prioritisation tools.**

	Urgent – **I have to do today**	**Not urgent –** **it can wait for tomorrow/next week**
Important	Start with these tasks	Don't leave this box to the last minute
Not important	Sometimes these things take up unnecessary time – can they be delegated?	Don't put your self-care and leisure tasks all in this box…

Things I have to do	**Things I would like to do**	**Things someone else could do**	**Things that could be done if I have energy left over!**

Planning

Understanding what your priorities are can help you to plan your time and energy more efficiently.

As well as planning each day, it is good to consider how daily activities may impact on your energy levels over the week. For example, planned hospital appointments or visits with friends will require lots of energy. As some high energy activities such as these cannot be avoided, you may wish to plan a lower energy use day before or after.

I play my day rigorously; if I know I am going out in the evening I rest more in the day and vice versa. I have learned through experience how to achieve more of a balance.

The following tips may also be helpful:

- Organising and planning your environment can help you adapt tasks to reduce the amount of energy you use.
- Adapting your schedule may help you spread out activities across the day or over the week.
- Aim to have a mixture of high energy and low energy tasks each day.
- Plan regular rest periods, allowing you to recharge your batteries through the day.
- Using a daily or weekly planner can be a useful way of helping you to visualise if you have too much planned for one day.

Pacing

Pacing involves breaking larger and high energy use tasks into smaller more manageable chunks.

For example, high energy tasks can be broken down with rest periods, or even split over several days. Rather than planning to clean the house, you may plan to complete 15 minutes of housework each day. You can use a fatigue diary to help you identify how much time you can spend on a task before becoming fatigued. Planning for 15 minutes of activity for example, can help you avoid "pushing through" to complete the task despite feeling fatigued.

Breaking tasks down into essential parts, and planning tasks for times when you have more energy can also be helpful. For example, you could prepare vegetables in the morning, and leave them in water ready to cook in the evening when energy levels may be lower.

Pacing and planning can be particularly important if you are working. Having a balance between working from home and in the office can be hugely beneficial. Planning when you are office based is particularly important. It may be best to spread this throughout the week allowing a day or two to work from home in between.

Tips from people living with a condition

Cleaning one room at home rather than trying to clean whole house in a day. Shorter more frequent sessions gardening rather than longer ones.

I use pacing to clean my car – by cleaning a few panels each day, I can clean the whole car over three or four days which is very satisfying when I've achieved it.

I can make a plan to do sections of the garden over several days and then I don't get burnt out. The hardest bit is making myself stop when I feel like I could do more, but I have to make myself rest or I won't be able to do anything the next day.

Working from home means I can get up later, take more time getting ready as I don't have to travel to an office, I don't have to worry about long walks to the toilets/ coffee shop/meeting rooms, I don't have to get home late, prepare a meal when I'm tired after a long day, eat late in the evening.

Rest

Rest is one of the most important ways to manage fatigue. If you only rest once you become exhausted, it can take longer to recover.

Rest helps your body to recover from both physical and mental activities.

Getting the right amount of rest is important: too much rest can lead to lethargy; too little can lead to fatigue.

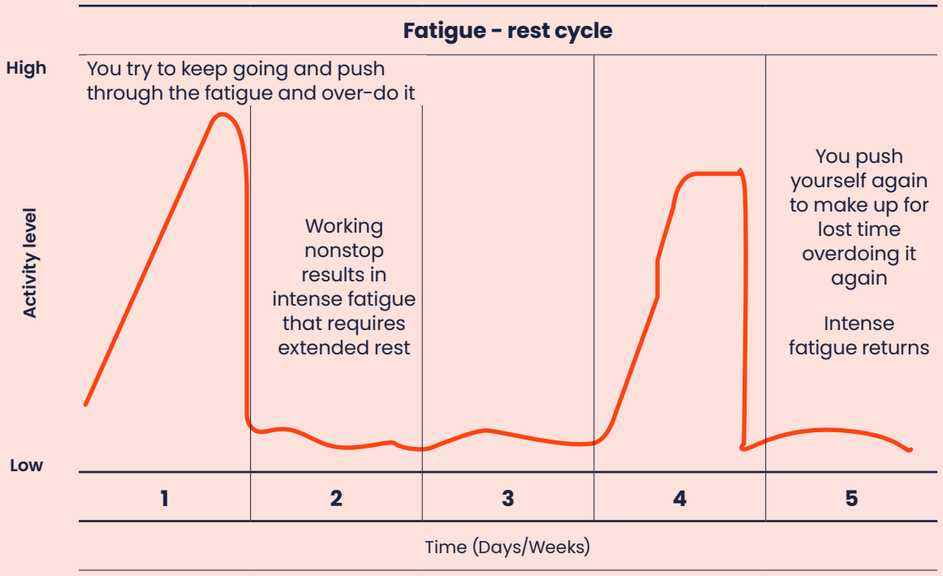
Sometimes resting means doing nothing at all.

- If you have difficulties with mental fatigue, tasks such as reading and listening to music may also use up energy. Using relaxation techniques can be a structured way to rest.
- Try to plan your rest time into your day in advance and stick to this where possible.
- Taking regular short rests of 10-15 minutes can help to avoid becoming fatigued later in the day and can increase your endurance overall.
- Taking three to four short rests through the day can help keep some energy in your energy bank.

Just taking time out to be quiet for about ten minutes.

I find when I'm doing a lot of cooking or gardening, I have to keep on having to have little sit downs, to rest my back.

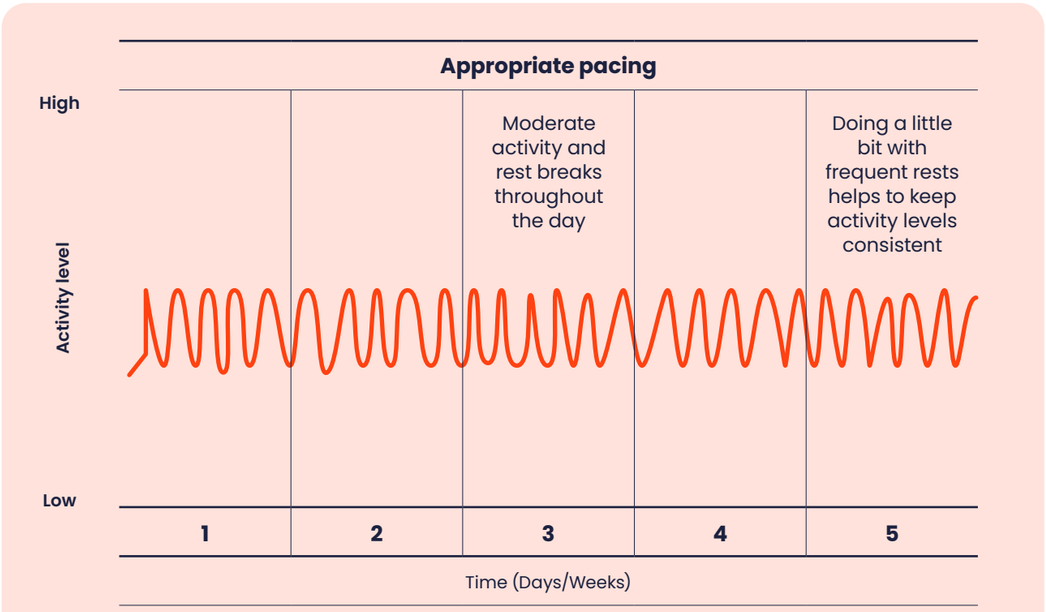
Lots of people with fatigue adopt a 'boom-bust' pattern of activity. This is where you have "good", very busy days with little rest, followed by days of doing very little or nothing at all due to exhaustion. **The graph below illustrates this:**



Using pacing techniques and having frequent rests can help to you complete activities without becoming overwhelmed by fatigue or completely crashing. Resting between activities, or keeping active for a set amount of time, can allow you to achieve the same level of activity as with the boom-bust cycle, with activity more evenly spread over the day or the week.

The graph below shows the impact of pacing and resting throughout the week.

I just take some time out while in my wheelchair, to sit quietly and rest my head against my head rest.



Some examples of restful activities identified by people with a condition:

- Reading
- Listening to music or audio books
- Doing a hobby (e.g.: making jewellery, sewing, papercraft, adult-colouring, playing an instrument etc.)
- Practicing mindfulness
- Doing a jigsaw puzzle
- Photography
- Watching TV
- Having a bath
- Sitting outside or taking the dog for a short walk

Delegating

Delegating tasks to others can help save energy for tasks you can achieve, rather than needing to struggle with tasks you find difficult.

It can be hard to ask for help, but continuing to struggle with difficult tasks can leave you feeling low in mood and demotivated. By asking for help, where this is possible or appropriate, you may be able to complete priority tasks and those you enjoy. This may in turn help lift your mood.

Delegating can work best if used regularly rather than as a one-off. For example, using a cleaner once a week can be a sign of resourcefulness.

I allow my carer to do more of my personal care and household tasks.

Top tips for energy conservation

Dos

- **Try to put tasks in order of priority** so that those that must be done are completed before you run out of energy.
- **Make a daily or weekly timetable** of activities that need to be completed.
- **Spread high energy and low energy tasks** through the day or week.
- **Set yourself realistic targets.**
- **Break down large, complicated tasks into smaller chunks** that can be spread through the day or week.
- **Learn to say no and to ask for help.**

Don'ts

- **Overdo it** when energy levels are high and pay for it later.
- **Feel you have to push through** and finish tasks in one go.
- **Do too little** and feel lethargic.
- **Only use your energy for jobs or chores,** make sure to save energy for things you enjoy!
- **Complete strenuous tasks** when you have very little energy.
- **Leave things to the last minute** – plan ahead.

Adapting daily activities

There are ways to adapt everyday activities to make them more energy efficient. These changes can be common sense, but people often continue to complete activities in the way they always have.

Could any of the simple changes below help you?

Bathing and dressing

- Having a bath may increase your fatigue – showering may be a useful alternative.
- Plan the time of bathing to suit your energy and lifestyle.
- You may find a good-quality towelling bathrobe allows you to dry with less effort.
- Sit down to dress where possible.
- Equipment may also be useful e.g. shower stool, grab rails or a long-handled shoe horn.
- Consider the clothes you wear - casual clothes with fewer fastenings are often easier.

Eating and meal preparation

- Avoid large meals late in the evening.
- Sit with your legs, back and perhaps arms supported when eating.
- Keep frequently used items within easy reach.
- Plan ahead to reduce cleaning e.g. line baking pans with foil.
- Prepare extra to freeze or use ready meals for days where you have other tasks to prioritise.
- Avoid lifting – slide pans across worktop or use cooking baskets where possible.
- Use sieved inserts in pans for boiling food to save lifting hot heavy pans.
- Break down activities, planning these when you have more energy. For example, prepare vegetables in the morning
- Minimise preparation where possible. For example, buy pre-chopped vegetables.
- Sit down to complete sections of the task or use a perching stool.

Laundry and housework

- Spread smaller loads through the week rather than trying to complete on one day.
- Sit down to iron.
- Ensure the clothes line is the correct height and place washing basket on a chair to avoid bending down.
- Consider labour saving devices, such as a tumble drier and a dishwasher.
- Spread out cleaning tasks through the week or month.
- Alternate high energy cleaning tasks with low energy ones.
- Consider outside help or break tasks down into several steps.
- Use equipment to avoid bending, such as a long-handled dustpan and brush and lightweight vacuum cleaners.

Shopping

- Use the same shop on a regular basis to learn where items are for easier shopping.
- Shop at quieter times.
- See if there is a shop mobility schemes near you.
- Try to avoid carrying large heavy objects: can someone assist you?
- Use online shopping or click and collect.
- Consider several smaller shops rather than one weekly shop.

Leisure and gardening

- Make time for things you enjoy with a rest after.
- Plan social occasions so that they don't occur in a row.
- Take control of social situations by suggesting to friends what you would like to do.
- Keep gardening simple and easy to manage with low maintenance.
- Consider relevant equipment, such as raised flower beds.

Take note

Talk to an occupational therapist if you need further support in adapting any daily activities, or for advice about equipment. You can refer yourself to your local social services occupational therapist if you need equipment.

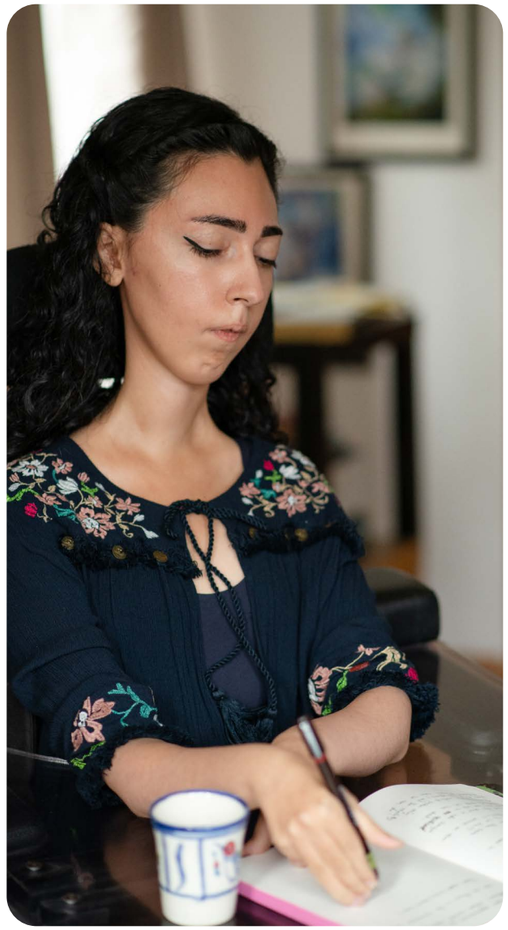
Key points:

- Avoid the boom-bust cycle by pacing activity throughout the day.
- Resting before you feel tired is a good way of combating fatigue.
- Planning ahead is important to ensure you don't overdo it.
- Prioritise tasks which are most important to you.
- Learning to delegate can help you save energy for tasks you enjoy.
- The use of aids or equipment can help you to save energy.

Further information:

Royal College of Occupational Therapists (RCOT) - How to conserve your energy.

https://www.rcot.co.uk/lift-up-your-everyday/lift-up-your-everyday-by-managing-energy



Section 9:
Goal setting and making changes

Making changes to your routine and lifestyle can be very difficult. There is a useful exercise in the appendix (Worksheet 7 – The Wheel of Life) which can help you think about changes you can make to reduce the impact of fatigue on your day-to-day life.

This document contains lots of ideas and tips to help you manage your fatigue. It might be a good idea to spend some time reflecting on what is most useful or relevant to you. **Below are some questions to help you start thinking:**

- What strategies, skills and tips have I found **most helpful?**
- What could be **triggering or contributing** to my fatigue?
- What seems to **alleviate or lessen** my fatigue?
- Are there particular **areas** of my life related to fatigue that are **most in need of attention?**
- Are there particular barriers that get in the way of managing my fatigue? What are my **'trouble spots'?**

Setting small step-by-step goals can be a useful way to help you begin to make changes. You can effectively formulate these goals by using the SMART goals method.

SMART goals method

S	M	A	R	T
G	O	A	L	S
Specific	**Measurable**	**Achievable**	**Realistic**	**Timely**
What do you want to do?	How will you know when you've reached it?	Is it in your power to accomplish it?	Can you realistically achieve it?	When exactly do you want to accomplish it?

Some examples of SMART goals for fatigue management:

1.

Over the next two weeks **I will practise a relaxation technique** three times a week.

2.

I will avoid afternoon naps and set-up a bed time routine which starts at 10pm each evening for the next three weeks.

3.

I will stop to take a rest when cleaning the house after 20 minutes over the next three weeks.

Benefits of setting goals and targets

Helps me not to feel overwhelmed when I have a lot of tasks that need completing.

It helps to keep me motivated.

It helps me organise myself and structure my day.

Gives me a focus.

Sense of achievement when goal/ target reached.

General satisfaction of pushing myself to keep as active as I can for as long as I can.

It is important to be kind to yourself, making changes to your life is not easy.
Even making one small, positive change is an achievement!

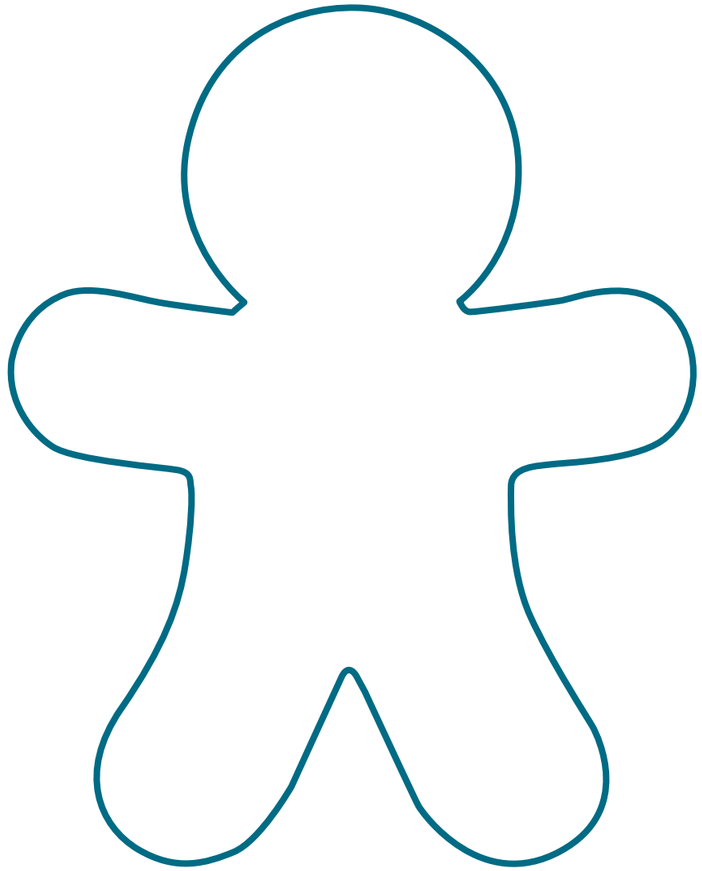
Key points:

- Adapting your lifestyle to live with fatigue takes time.
- Set yourself small, realistic targets.
- Don't try to change everything at once, start with one or two small changes first.
- Consider what is most important to you and start here.
- Revisit the sections in the booklet at different times to help refresh the concepts.

Section 10:
Appendix

Worksheet 1 – Understanding and describing your fatigue

Gingerbread-man exercise



Use the picture to write or draw how your fatigue impacts on you.

This could be physical symptoms, your thinking or your emotions – try to think as broadly as possible.

Use the space below to write down your own definition of fatigue

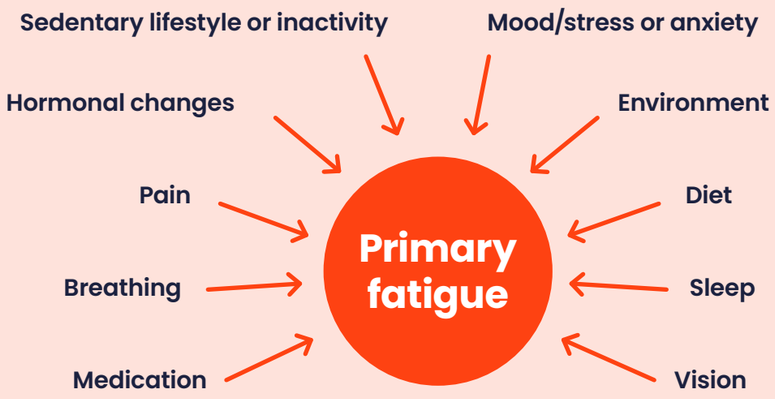
Worksheet 2 – What causes my fatigue

Primary fatigue – muscle tiredness and weakness

Write down a list of tasks where you have noticed that your muscles tire quickly:

Secondary fatigue

Circle each factor which you think contributes to your fatigue – you may want to focus on these sections in the document.



Worksheet 3 – Fatigue diary

Activity and fatigue diary:

- Record what activities you carry out each day
- Score how fatigued you are at the end of the day
- Score how fatigued you are at different points in the day
- Maintain diary for two weeks

Reflection:

At the end of two weeks reflect back on the diary to identify patterns like:

- Which activities make you most fatigued
- When do you have long periods of inactivity
- Where might you be able to split activities to manage fatigue
- Where might you be able to introduce activities to break periods of inactivity

Planning:

With this information, plan your activities:

- Spread out activities through-out the week
- Plan activities to avoid 'boom bust' activity cycle.
- Introduce activities to break up periods of inactivity.
- Introduce gradual exercise

Worksheet 3 – Fatigue diary

Beginning: _____ **Week:** _____

Fatigue diary

Please keep a record of your daily activities and their effects on you in terms of your fatigue levels. Use the following ratings to record how you feel.

1 = No fatigue **5** = Moderate fatigue **10** = Severe fatigue

	Wake up time	Morning	Afternoon	Evening	Sleep time	Comment about sleep
Monday						
Fatigue rating						
Tuesday						
Fatigue rating						
Wednesday						
Fatigue rating						
Thursday						
Fatigue rating						
Friday						
Fatigue rating						
Saturday						
Fatigue rating						
Sunday						
Fatigue rating						

Worksheet 4 – Thought diary

Situation	**Unhelpful automatic thoughts** 0-100	**Emotions** 0-100	**Alternative thoughts** 0-100	**New ratings for original automatic thoughts and emotions** 0-100
Think about: • Where are you? • What are you doing? • What time of day is it? • Are you alone or with others? • What has happened?	**What is going through your mind?** • If more than one thought occurs, underline the most powerful one.	**Are you feeling:** • Low or sad? • Guilty? • Worried, tense, anxious? • Angry? • Irritable? • Ashamed? etc. • Underline the most powerful emotion that you are feeling.	**Weigh up the evidence for and against the automatic thought, are there any alternatives?**	

Situation	**Unhelpful automatic thoughts** 0-100	**Emotions** 0-100	**Alternative thoughts** 0-100	**New ratings for original automatic thoughts and emotions** 0-100

Worksheet 5 – Soft stomach breathing

(also known as abdominal breathing, deep breathing or diaphragmatic breathing). From Ray Mulry (1995) In the zone: making winning moments your way of life. Great Ocean Publishers, US.

Sit with a straight, vertical back (as opposed to a slumped position). Take a deep breath as you inhale through your nose. Hold it.

Did you pull your stomach in, or did you push it out? Now exhale.

A common response is, "I pulled my stomach in." This is not what you want to do. When you pull your stomach in, you restrict space needed by your lungs for full expansion.

So, try another breath, only this time, "push your stomach out" as you gradually inhale:

- Slowly inhale through your nose to the count of four, pushing your stomach out. Hold it briefly.
- Slowly exhale through your mouth to the count of eight, and relax.

This is actually the way you breathe as you sleep. It is natural for your stomach to slowly expand and then relax into a flat stomach position.

Do three more deep soft stomach breaths. Notice the feeling of relaxation gradually settling over you. Your heart rate is slowing down and becoming more rhythmic. Your blood pressure is decreasing. You feel less pressured. You are reducing physical tension.

Soft stomach breathing is easy to do and can be done almost anywhere, at any time during your day. Try soft stomach breathing to start the day and then repeat it several times throughout the day. Soft stomach breathing can also help you relax just before an event that might be stressful.

With relaxed breathing air flows smoothly in and out of the lungs rather than being drawn in forcefully and blown out with equal force. With soft stomach breathing the stomach rises with each breath in and lowers with each breath out. You can check this by putting one hand on your chest and the other on your stomach as you breathe in and breathe out. If only the hand on your stomach is moving up and down, you are probably breathing correctly. If the hand on your chest is also moving up and down, you may want to practise a little more until your breathing becomes more relaxed.

Worksheet 6 – Constructive worry exercise

Putting the day to bed with constructive worry

Bad stuff

Good stuff

To do

Worksheet 6 – Constructive worry exercise

The bad stuff:

This is a place to write down anything negative that is on your mind and you think may interfere with your sleep. Try to be as specific as possible. You can, if you wish, develop this further by describing why you feel anxious, upset, angry etc.

The good stuff:

This is a place to write down anything that went well or that you enjoyed today, anything that you are looking forward to, anything that you feel grateful for or that makes you happy etc.

To do list:

1. **Write down the tasks** you know you need or want to do the next day.
2. **Constructive worry:** Go back to the bad stuff column and for as many of the items there as possible write down one, single, realistically achievable action you can take the next day to start addressing it. Don't try and solve everything in a day; only write down tasks you know you could realistically tick off the next night. For example don't write down, "Find a new job," – that will never happen in a day! Rather, you may write "Find my CV on the computer."; the next night you may write, "Update my CV"; the next night, "Look up three recruitment agencies"; the next night, "Email my CV to those agencies" etc.
3. **Do the exact same thing with the good stuff column** i.e. write down any actions you can take tomorrow to reinforce and amplify the positive things.
4. **Prioritise:** Next to each task write one of three letters: **E, D or O for Essential, Desirable and Optional.**

   Remember that an item only gets an E if there is a realistic chance of something bad happening if you don't do it.
5. **Always, always, always check your to do list in the morning!!**

Worksheet 7 – The wheel of life

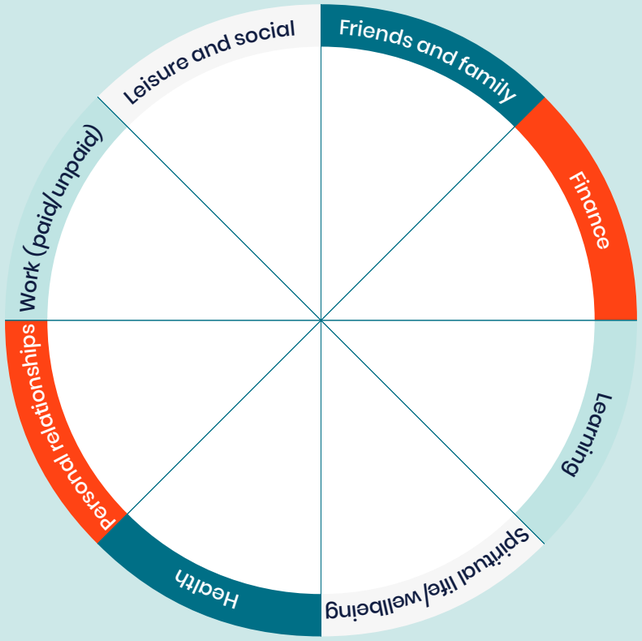
Finding a balance between the different areas of our lives if often difficult. At times, one area may take up more of our time and energy and this is to be expected, however, if the imbalance continues for a sustained period of time then other areas can miss out.

The wheel of life helps you look at the balance between your areas of life, and help you prioritise activities which you would like to participate in again. This is a dynamic process, and will be ever changing so you can repeat this exercise at different times.

Score each segment of the circle out of 10 for how satisfied you are with that area
0 = least satisfied, 10 = most satisfied.

Look at the segments that scored the lower and ask:

- What would 10 out of 10 feel, look and sound like to you?
- Is that unrealistic?
- How would your life be different if you scored 10 out of 10 in that area?
- What can you do to move your score up just one point?
- Use the space below to write some notes in answer to these questions.



Notes

Worksheet 7 – The wheel of life

Learning to deal with setbacks

Most people with fatigue will experience setbacks, setbacks meaning - times when symptoms worsen for a period of time. It can be difficult to maintain your levels of activity during these times. Different things will provoke setbacks, and they may last for differing lengths of time. Each person will have different ways of dealing with a setback. The purpose of this handout is to encourage you to become aware of those things that provoke a setback for you, and to develop a plan for coping with a setback when it happens.

What can cause setbacks:

- Stress
- Low mood
- Period of illness
- Over doing it

It is worth recognising as many signs and characteristics from your own experience of setbacks to help you next time. Use the space below to list those warning signs which you have noticed before, and add any new ones as you become aware of them.

Warning signs e.g.:

How to react to warning signs to prevent a setback:

Section 11: **References**

1. *184th ENMC international workshop: Pain and fatigue in neuromuscular disorders* 20–22 May 2011, Naarden, The Netherlands, 2011.
2. Ramdharry GM, Thornhill A, Mein G, et al. *Exploring the experience of fatigue in people with Charcot–Marie–Tooth disease.* Neuromuscular Disorders 2012; 22: 208-213.
3. Kalkman JS, Schillings ML, van der Werf SP, et al. *Experienced fatigue in facioscapulohumeral dystrophy, myotonic dystrophy, and HMSN-I.* J Neurol Neurosurg Psychiatry 2005;76(10):1406–9.
4. Schillings ML, Kalkman JS, Janssen HMHA, van Engelen BGM, Bleijenberg G and Zwarts MJ. *Experienced and physiological fatigue in neuromuscular disorders.* Clinical Neurophysiology 2007; 118: 292 –300.
5. Veenhuizen Y, Cup EHC, Jonker MA, et al. *Self-management program improves participation in patients with neuromuscular disease A randomized controlled trial.* Am Academy of Neurology 2019; 93:1720-1731.
6. FACETS programme: Written by Sarah Thomas, Peter W Thomas, Alison Nock, Vicky Slingsby, Roger Baker and Charles Hillier and funded by the MS Society.
7. *The Royal Hospital for Integrated Medicine (RLHIM) Cognitve Behavioural Therapy for Insomnia Program*: Written by Dr David O'Regan & Dr Hugh Selsick.
8. Hilton-Jones D, Bowler M, Lochmuller H, Longman C, Petty R, Roberts M, Rogers M, Turner C, Wilcox D. *Modafinil for excessive daytime sleepiness in myotonic dystrophy type 1 – the patients' perspective.* Neuromuscualr Disorders 2012;22(7):597-603.
9. McNicholas W, Hansson D, Schiza S, Grote L. *Sleep in Chronic respiratory disease: COPD and hypoventilation disorders.* European Respiratory review 2019; 28.
10. Böing S & Randerath W. *Chronic hypoventilation syndromes and sleep-related hypoventilation.* Journal of Thoracic Disease. 2015; 7(8).
11. Grigg-Damberger M, Wagner L, Brown L. *Sleep hypoventilation in patients with neuromuscular diseases.* Sleep Medicine Clinics. 2012.
12. Atik D. *The effect of breathing exercise on fatigue and stress in patients with coronary artery diseases: A randomised controlled trial.* La Prensa Medica Argentina 2016; 102:2.
13. Mulhaeriah, Yati Afivanti, Engkus Kusdinar Achmad, Moh Syafar Sangkala. *Effectiveness of relaxation breathing in gynaecological cancer patients undergoing chemotherapy.* International Journal of Nursing Sciences. 2018; 5(4).
14. Chan J, Ho R, Chung K-F, Wang C-W, Yao T-J, Ng S-M, Chan C. *Qigong exercises alleviates fatigue, anxiety and depressive symptoms, improves sleep quality and shortens sleep latency in persons with chronic fatigue–like illness.* Evidence based Complementary and Alternative Medicine. 2014.

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