



▶ **Myalgic
Encephalomyelitis/
Chronic Fatigue Syndrome
(ME/CFS) Service**

**Treatment manual
Name:**

If you are unable to attend a session, please
contact the team in advance on 0114 226 3232.

Flare Up Plan

HOW DO I KNOW I AM STARTING TO EXPERIENCE A FLARE UP

What are my usual signs and symptoms?

WHAT ARE MY USUAL TRIGGERS FOR A FLARE UP

WHAT CAN I DO TO HELP.....

ACTIVITY MANAGEMENT

Consider **Pacing** back activities or splitting baselines. **Plan** your week, **Prioritise** what needs doing and what can be left until later. Consider physical, mental and social activities.

QUALITY REST

Are you having quality rest? Consider increasing frequency and or duration of quality relaxation and pauses.

EMOTIONAL STRESS

Seek out and prioritise activities that stimulate your 'soothe' centre.

THOUGHTS

What thoughts are likely to pop up, how will you respond?

COMMUNICATION

Consider telling people you are having a flare up, how you intend to manage it and what they can do to help.

OTHER THINGS THAT MAY HELP ME....

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Introduction

This manual is designed to help people who are living with ME/CFS. It is a resource intended to provide information and support about the diagnosis, symptoms, and management of ME/CFS.

ME/CFS can have a significant impact on ALL aspects of an individual's life. Activities including work, socialising, engaging with hobbies and interests may be significantly limited or stopped. The effects of ME/CFS can affect relationships with family, friends, and colleagues, who may not understand the condition and its impact. Living with the ME/CFS may also affect mood and may cause significant levels of distress.

For many people with ME/CFS it has taken a long time to receive a diagnosis. Lack of understanding and awareness about ME/CFS means people can experience misunderstanding, scepticism, false hope, unhelpful advice and even discrimination, from friends, family, health and social care professionals and employers.

It is normal to feel sceptical and wary, you may have been told lots of different and conflicting things about ME/CFS in the past. The techniques in this manual may be seen as a tool kit. Used together they can be a safe and effective way of managing your ME/CFS. All the information and strategies in this manual are based on the current evidence base for interventions for ME/CFS.

This approach is not a cure for ME/CFS; it is about making small, consistent adaptations to our behaviours, which can make a big difference to the experience of living with ME/CFS. We work with you as a whole person, not just a collection of symptoms, to help you develop an individualised, flexible approach.

All information sessions on the treatment programme are covered in this manual. It is important to bring it to each session. Feel free to make notes in the manual to make it more personal to you. It can be useful to help you plan and reflect on the changes you make during the programme. You may find it useful to share the information with those around you such as family and friends, health care professionals, employer, and colleagues. Their support and encouragement will be invaluable as you try to make changes.

No one wants, chooses, or deserves to have ME/CFS, but you do have choices about how you respond to it, which can in turn influence your experience of living with the condition.

SESSION 1

What is ME/CFS

ME/CFS stands for Myalgic Encephalomyelitis or Encephalopathy (ME) / Chronic Fatigue Syndrome (CFS). In the past it has also been known as Post Viral Fatigue Syndrome (PVFS). In recent years the term Systemic Exercise Intolerance Disorder (SEID) has also been used, particularly in the United States.

The term 'ME' seeks to explain the processes and structures thought to be involved: Myalgic (muscle) Encephalo (brain) myelitis (inflammation) pathy (dysfunction). The term CFS seeks to describe the symptoms experienced: Chronic (symptoms present more than 4 months) Fatigue (primary and dominant symptom, different from feeling tired) Syndrome (a term for medical conditions whose causes and processes are not fully understood).

The World Health Organisation classifies ME/CFS as a neurological condition. However, there is much debate about the underlying causes of ME/CFS. Current theories include nervous system dysfunction, autoimmune dysfunction, mitochondrial dysfunction, viral infections, and genetic factors. What is agreed is that **ME/CFS is NOT a progressive disease process**. There is no structural damage to the body; rather it is the function of physiological systems that is affected.

ME/CFS is a **long term, fluctuating** condition in which symptoms can vary in severity. The dominant symptom is **persistent, debilitating physical and mental fatigue**, which is different from ordinary tiredness, in that **energy levels are not restored by sleep**. Individuals with ME/CFS experience '**Post Exertional Malaise**', which is a delayed, disproportionate and prolonged increase in symptoms in response to increased levels of physical or mental exertion.

Other commonly experienced symptoms may include widespread pain and discomfort, frequent illness, digestive symptoms, poor sleep, cognitive processing difficulties, anxiety, low mood, problems with temperature regulation, palpitations and hypersensitivity to sensory stimulus, this list is not exhaustive.

Most people with ME/CFS improve over time and many will recover and resume normal activities. Because of the complexity, fluctuating nature and spectrum of symptoms associated with ME/CFS it can be hard to predict outcomes. However, the **evidence indicates that modifying behavioural responses can improve outcomes for quality of life**.

There is no specific diagnostic test for ME/CFS. A diagnosis is based on an individual's history and clinical presentation when other medical causes of fatigue have been excluded and symptoms have persisted for four months.

Research into ME/CFS has helped us to understand factors which are associated with being more likely to develop the condition (**predisposing**), factors which are linked to the onset of symptoms (**precipitating**) and factors associated with maintaining and driving symptoms (**perpetuating**).

Predisposing factors include genetics, lifestyle, hormonal, personality types (?). Precipitating factors or triggers for onset include: physiological stress (e.g. Viral infection), physical stress (e.g. trauma/surgery), excessive or prolonged physical or mental demands and emotional

stress (e.g. significant life events) past or present emotional trauma. Perpetuating factors which help maintain symptoms may include on-going physical, mental and emotional stress, poor sleep, repeated infections / illnesses, poor nutrition, deconditioning, social isolation, low mood.

Dysregulation Model

ME/CFS is a multi-system illness that affects many different aspects of the bodies physiology. Current research indicates dysregulation of several systems in the body which may explain the wide range of symptoms people can experience.

Our bodies are constantly responding to the demands of life, combining information from internal systems in the body and information from the external environment. The body responds dependant on the needs at the time, either active or restorative to help the body return to a stable state. This state is referred to as homeostasis. **Homeostasis is the body maintaining balance** to provide ideal internal conditions for long term health and survival.

Demands on the body are many and varied: Everyday **internal demands** such as hunger, thirst, physical and cognitive activity, processing emotions, sleep. Additional internal demands that occur during infection, inflammation, injury and disease. The body also needs to respond to everyday **external demands** including gravity and temperature change. Demands can be increased by disruption to daily patterns which affect circadian rhythms known as our body clock due to sleep disruption, lack of daylight exposure, changes in eating patterns.

The body's response to demands, change or needs is achieved by regulating various dynamic systems at a body wide and cellular level. At a body-wide level three of the systems involved are the **Autonomic Nervous System** (neurological), the **Hypothalamic Pituitary Adrenal (HPA) Axis** (neuroendocrine), and the **Immune System** (inflammatory) which work together to coordinate a response to change or demand. At a cellular level, the processes of the **Metabolic System** are involved. All these systems are interconnected and activated when there is an increase in demands for example an infection, excessive physical stress or an emotional trauma. Activation leads to physiological and behavioural changes to maximise healing and recovery whilst protecting the body from further threats at a time when vulnerable. The activation of the HPA axis in response to stress can lead to immune responses, often felt as sore throats, swollen glands. In post viral onset it is observed that once the infection has stopped the body remains over responsive to benign input

A metaphor that can help understand these complex physiological processes is that of a faulty smoke alarm system. It is initially set off by smoke but once the smoke has gone it can keep being set off for no apparent reason. It is having a normal response but at an inappropriate time and to an excessive degree. When we have increased demands on the body we activate multiple systems, however if the communication between the systems is interpreted as a threat, the body goes into protective mode and activates the various systems accordingly. This means other physiological systems that help to downgrade our body's response are not easily engaged. This is exhausting and disrupts sleep and activity patterns further.

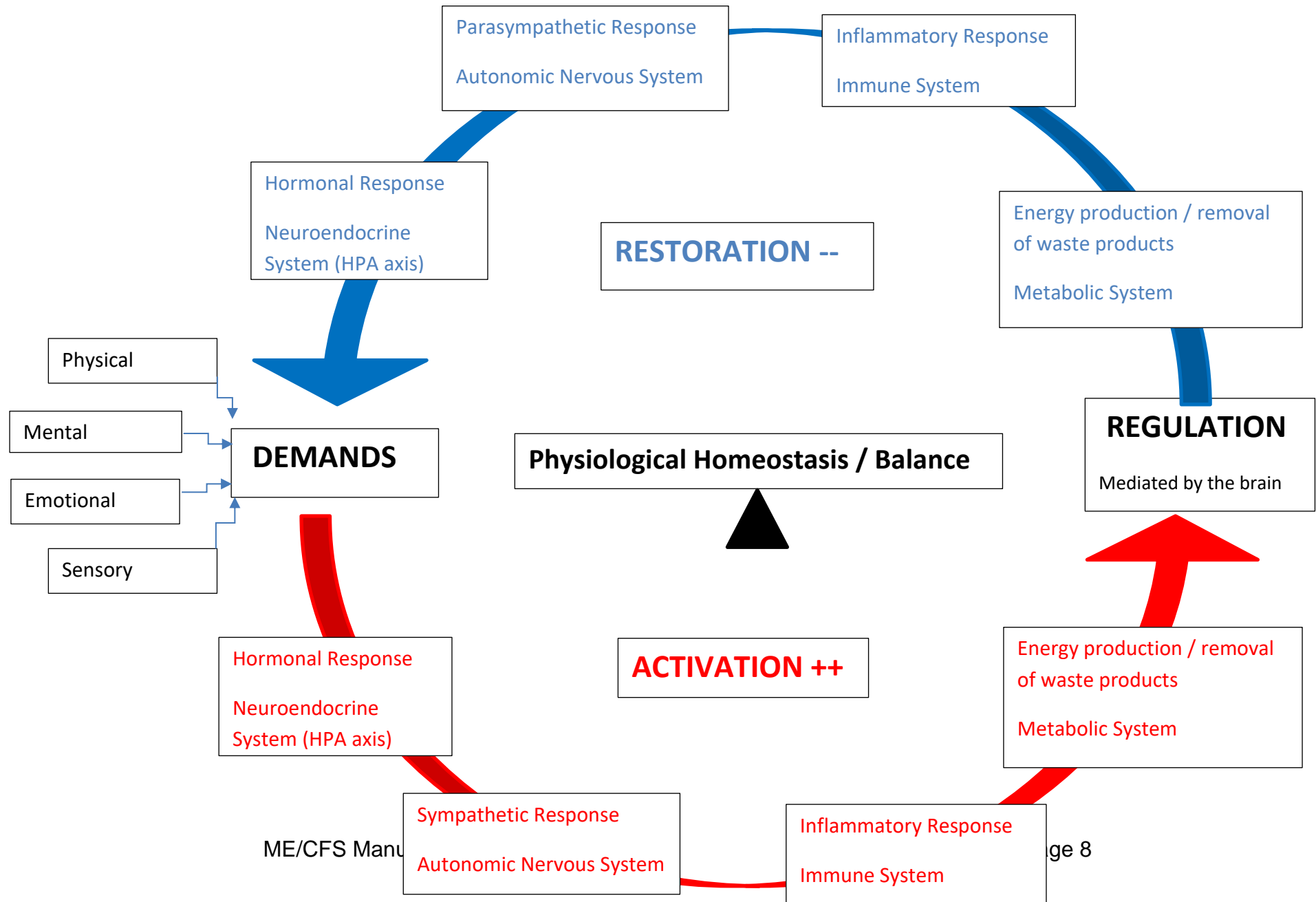
What can be done about dysregulation?

As these are complex systems that need to regularly adjust and change in response to demands and our world, it is difficult to find one factor that will correct dysregulation. However, we know factors that can aggravate dysregulation along with strategies that can improve stability and support homeostasis. The approaches that can be helpful to therapy include:

- Activity management: matching energy available and energy expenditure, understanding that there are different energy demands for different types of activity. It is important to work with the energy you have currently, not push beyond it.
- Balancing and managing overall demands and activity to remain within limits and allow recovery, reducing the impact of a boom-and-bust pattern.
- Recovery time for quality restorative rest following exertion.
- Desensitisation of the sympathetic nervous system and increasing the parasympathetic response.
- Physical activity within tolerance levels to reduce secondary effects of deconditioning.
- Regulation of the body clock and circadian rhythms, including sleep, light and eating patterns
- Supporting orthostatic tolerance through fluid levels and management techniques.
- Ensuring diet is providing appropriate nutrients and delivered in different ways, for example eating smaller portions more often, supports regulation of blood sugar levels.

Initially the focus is on consistency and regulating, to support stability before increasing the level of demand. This should be done gradually allowing development of tolerance and adaption prior to any further increases in demand, to enable the body to rebalance.

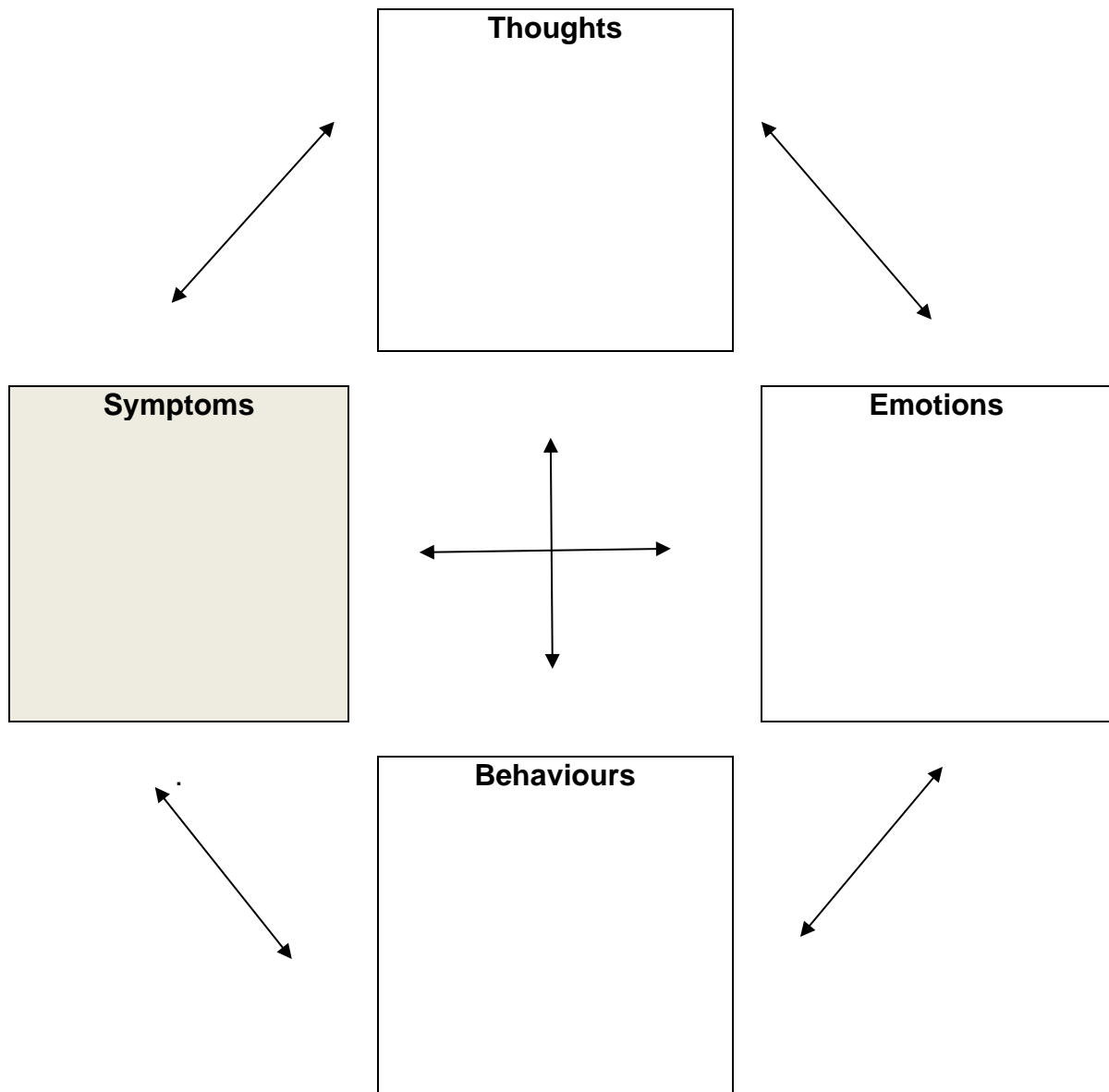
Dysregulation Model of ME/CFS



How does ME/CFS affect me?

People with ME/CFS report that their symptoms affect many aspects of their life including their behaviours, (what you do and how you do it, includes work, rest, leisure and relationships), thoughts and emotions.

Hot Cross Bun: Write in each box how your ME/CFS has affected you.



Primary Suffering = Fatigue

Secondary Suffering = Everything else!

Our Approach

What have I tried so far

Before starting this approach it can be helpful to reflect on what you have tried so far in an attempt to manage your fatigue. Consider what you have tried, did it help reduce fatigue or improve your quality of life? If helpful was that short or long term? Were there any cons involved? This may include financial costs, time, hopes raised etc.

Things I have tried	Pros / Benefit	Cons / Cost	Ultimate Result

Biopsychosocial Approach

A traditional medical approach to health conditions focuses on physical symptoms in the body and medical treatments, typically medicine or surgery to control or cure those symptoms. There is currently no medicine (or surgery!) to treat ME/CFS. A biopsychosocial approach considers the interactions between the physical (biological/physiological), psychological and social/behavioural aspects of an individual's experience of a health condition. **The focus is on influencing rather than controlling or fixing symptoms.**

This approach is likely to be different from what you have experienced before. The techniques and strategies used have been extensively researched and proven to be beneficial for people living with long term health conditions, such as ME/CFS. The biopsychosocial approach has been shown to improve quality of life.

Acceptance

Some people with ME/CFS feel as there is no 'medical' treatment for their symptoms their only options are to 'give in' or 'fight' the condition. Our approach offers an alternative option, where your fatigue is not an obstacle to living a valued life.

Acceptance acknowledges your experience is real and difficult. In acceptance we are willing to have fatigue, even though we do not want it. This allows us to give up the 'fighting' and struggling which is very energy demanding and can help to minimise the secondary suffering that struggling causes, so that we can focus instead on what matters to us, what brings value to our life.

Acceptance is an on-going process, a willingness to be open to your on-going experience in the knowledge that you don't have to like it. It gives the opportunity to move towards your goals and values and make choices to live your life fully, and completely, day to day with fatigue.

Mindfulness

Everyone whether they have ME/CFS or not, spends a lot of their life on **'automatic pilot'**. We all have had the experience of travelling a familiar route before realising that for miles you have been totally unaware of our surroundings. In the same way, we may not be really 'present' moment-by-moment for much of our lives. This is completely normal and often harmless but it can cause us problems. 'Mindfulness' is the opposite of being on automatic pilot; it involves intentionally bringing awareness to your experience here and now, with an attitude of openness, curiosity and kindness.

When faced with difficulty such as living with persistent fatigue we can spend a lot of time thinking about the past and 'what we used to be able to do' or worrying about the future and 'what is going to happen'. This can mean we miss out on what is going on in our lives day to day. On automatic pilot events can trigger habitual patterns of thinking and acting, of which we may be only dimly aware; these may be unhelpful in coping with our fatigue and cause us additional emotional stress.

By becoming more aware of our thoughts, feelings and body sensations, from moment to moment, we give ourselves the possibility of greater choice not to respond automatically. When we are no longer operating automatically our experiences can change. We can learn to gently turn towards our experience rather than resisting it and struggling against it as we often do.

Mindfulness has been shown to improve energy levels, reduce pain, build self-esteem, enhance mood and improve immune system function. It can also lower blood pressure and may even reduce some of the thinning of certain areas of the brain that occurs with ageing.

We develop mindfulness through practice. We practice becoming more aware of where our attention is, and practicing focusing our attention over and over again. Mindfulness practice can be described as simple but it is not easy. Developing mindfulness skills takes patience, kindness and practice. Over the course of the programme we will introduce you to a variety of practices to train our ability to pay attention at will and in a certain way.

Mindfulness Practice

Awareness of Breath

In this practice we bring attention to our breath to anchor our awareness in the present moment. We are not trying to change the breath we are just going to notice it, as it is. When we notice our attention has wandered we gently and kindly return our focus to the next breath.

Values Based Goal Setting

Values

Our values guide how we live our lives; they are the things that matter to us as an individual. They reflect how we want to behave and describe the sort of person we want to be. Our values give us a reason to make changes in our lives, they are the 'why' behind what we do. People who live their lives more in line with their values tend to be psychologically healthier.

When we first consider our values a common thought is: 'I don't even know what my values are'. We often lose touch with our values or feel remote from them when we are dealing with fatigue and related suffering. When we lose touch with our values we may begin to behave in ways that do not feel good to us.

To further help identify your values you may wish to consider the table of common values. Use a pencil, cross out boxes until you identify the three most important to you at this time.

Acceptance	Curiosity	Honesty	Respect
Adventure	Encouragement	Humour	Responsibility
Assertiveness	Equality	Humility	Romance
Authenticity	Excitement	Independence	Self-care
Beauty	Fairness	Intimacy	Self-development
Caring	Fitness	Justice	Sensuality
Challenge	Flexibility	Kindness	Spirituality
Compassion	Friendliness	Love	Supportiveness
Connection	Forgiveness	Order	Add your own
Contribution	Fun	Open-minded	Add your own
Courage	Generosity	Patience	Add your own
Creativity	Gratitude	Persistence	Add your own

Some questions to consider If you were living according to your values

- How would you behave differently?
- How would you treat others differently?
- How would you treat yourself differently?
- How would you treat your body?
- How would you talk to yourself?
- How would your character change?
- What sorts of things would you start doing?
- What sort of things would you stop doing?
- What goals would you set and work towards?

People develop values in different areas of their lives. The following exercise helps to consider what areas of your life you may wish to focus your energy and attention on. In the 1st column are examples of different areas of your life where you may hold values. In the 'Importance' column rate the importance of the area on a scale of 10, where 10 is the most important. In the 'Action' column rate out of 10 how much you currently attend to this area of your life, where 10 is more action. In the 'Concern' column subtract the action score from the importance score, the bigger the difference between what is important to you and actions in line with it, the greater the concern.

For example, my family is 10/10 importance and action is 9/10, most of my energy and actions are in line with this value. Health and wellbeing is also important to me 9/10, but I do not give much energy or attention to this and would score it 4/10. So I am more concerned about my value of health and wellbeing.

	Importance	Action	Concern
Family Relationships			
Intimate Relationships			
Health and Well-being			
Self-development			
Friendships			
Work/Career			
Spirituality			
Interests/Leisure/Fun			
Nature			
Add your own			
Add your own			

Goals

Our values are the direction we want our life to go, a bit like a compass point; we can always face the direction we want to travel. Goals can be considered the destinations we reach as we journey through life in our chosen direction.

Goals give us a measurable, achievable way to work towards our values. It can be helpful to choose a goal that will give you enjoyment. You may also find it useful to break larger longer-term goals down into smaller more workable goals

Goals can give us a sense of achievement, which helps build self-esteem and confidence. They can also provide a structure to move forward and help to motivate us to take action.

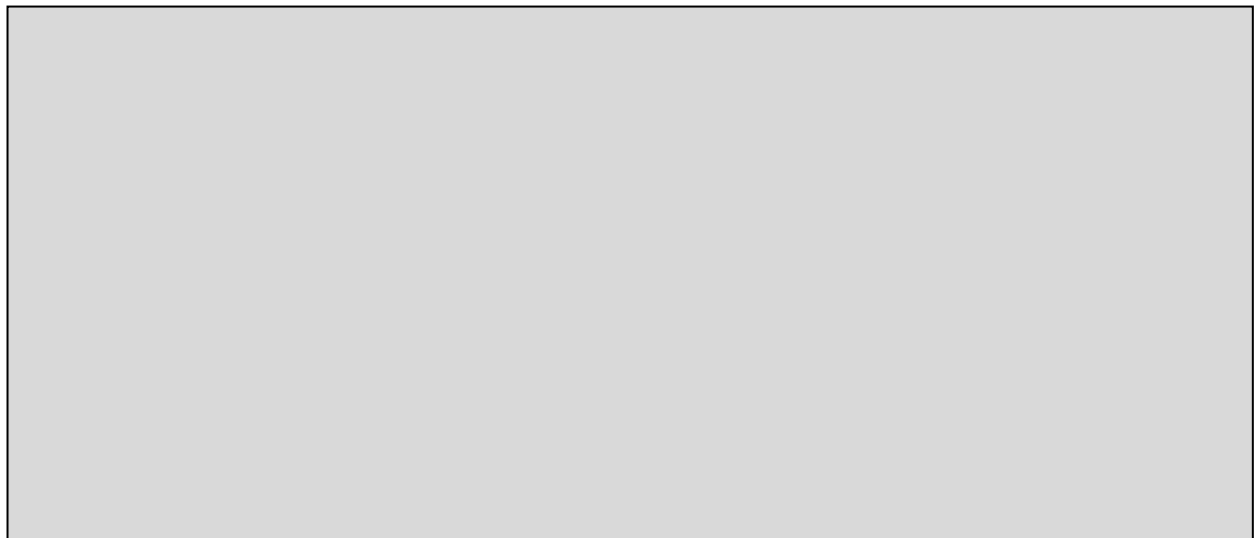
It can also be helpful to consider if your goal is 'SMART':

Specific	Is your goal too vague?
Measureable	How will you measure the amount you will do? E.g. distance, time, task.
Achievable	Is it something you can realistically achieve?
Realistic	Is this goal 'doable'?
Time limited	When do you want to have achieved your goal?

Session 1: Home practice suggestions.

1. Complete 'Awareness of breath' practice daily. You may wish to write down what you notice during the practice.
2. Complete values domain and identifying values exercises. Consider what values are important to you? Consider which value feels most neglected?
3. Write down a goal in line with one of the values you have identified that you may want to work towards over the following sessions.
4. Complete Activity Diary. Write down any trends you notice.

Session 1: Notes



SESSION 2

Activity Management

Review of Activity Diary

Review your completed activity diary, using the following questions as a guide:

- Are there any surprises?
- Are there any patterns or themes?
- Is there a balance between rest and activity?
- Do you spend most of your time on one particular type of activity?
- Which activity do you find most tiring?
- Is your day spent mostly resting? / Is there **any** rest during the day?
- How do you rest?

**Are your current activity levels working for you?
If not, what might be more workable, what changes could you make?**

Mobile Phone Battery Analogy

We can think of energy levels using a mobile phone battery analogy. If our mobile has a 'faulty' battery the charge or energy level is low, easily drained and takes a long time to recharge especially when the battery is flat. The fault is with the battery, not the phone.

Some activities drain our battery quickly whilst other activities may charge our battery. It may be helpful to plan and pace activities that deplete our energy levels and prioritise and incorporate activities that recharge or boost energy levels into our daily routine.

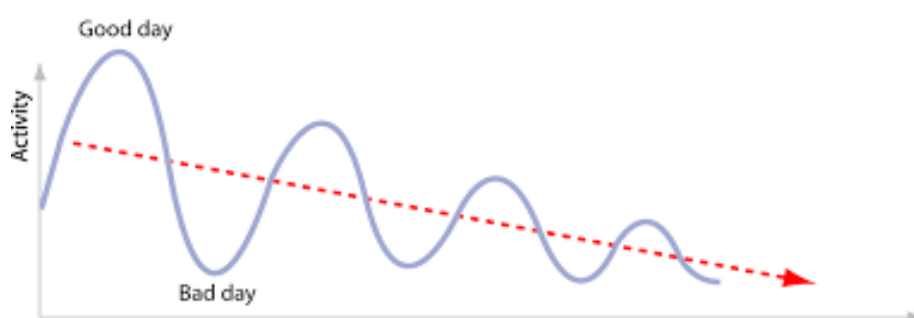
Consider what activities or situations charge or drain your energy levels.

Things that CHARGE my battery

Things that DRAIN my battery

Activity Patterns

We tend to develop habitual patterns of activity, what we do and how we do it. The Activity Diary can help us to identify patterns. A common feature for people with ME/CFS is the tendency to push to do as much as possible when energy levels are a little higher. This is understandable; doing a task can give us a sense of achievement. However, this burst in activity often leads to “pay back” or a “flare up” in symptoms forcing you to rest more in order to recover. This pattern of activity is sometimes referred to as the ‘boom/bust cycle’. Over time it may take longer to recover and overall activity levels tend to decrease



Alternatively, you may find yourself avoiding activities in an attempt to reduce your fatigue. This may include work, socialising, hobbies or other activities you have previously enjoyed. Reducing activity levels for fear of making our symptoms worse can lead to feeling that our lives have ‘shrunk’ and that we are just existing.

**Do you recognise these patterns?
Is it helping you live the life you would like to?**

Doing what matters.

When energy levels are limited, it is important to consider your values and priorities your activities, so you spend your energy on the things that are most important to you.

Typically, in ME/CFS fatigue controls what you do, how you do it and for how long. **PACING** is a strategy for managing activities that lets you make choices about how you approach what you do. Pacing strategies can be applied to physical, mental and social activities.

Pacing proactively means doing things differently from how you are currently. Reflecting on your values can help you to **PRIORITISE** which activities you choose to focus your energy on. Being aware of thoughts and emotions that may drive your habitual activity patterns can be helpful.

To make changes to your activity requires **PLANNING**, as it will not happen automatically. There are many different pacing techniques and approaches you may wish to explore. It may be helpful to use an activity diary to plan activities differently.

Pacing Tips

- Break tasks up into chunks (time or task).
- Take regular planned breaks throughout the day.
- Change activity type regularly.
- Change position regularly.
- Slow the tempo, reduce effort.
- Do some gentle stretches before, during or after task.
- Delegate, get help.
- Make use of equipment that helps.

Getting started - Activity Baselines

A baseline is how much of an activity you can do on a bad day WITHOUT flaring up your fatigue. It will be individual to you and it will vary depending on the activity. If used consistently activity baselines can help to reduce the number of flare ups experienced. You may gradually increase baselines over time.

A helpful analogy is to consider the braking distance for cars. When driving we apply the brakes BEFORE our car hits the car in front. The car's brakes need to be applied with enough time for the car to slow down and avoid a collision, in the same way we need to put the brakes on our activity before we experience an increase in symptoms, not once we start to feel the effects.

We work out baselines through trial and error. It is common to overestimate what your baseline 'should' be, and it can be frustrating sticking to a baseline when you feel like you could do more or are struggling to 'accept' the effect of ME/CFS.

A Flexible Approach

Nobody paces perfectly. Habits die hard and don't change overnight, so you will need patience. You may do more than you intended, for many good reasons, and experience an increase in symptoms. This is normal and frustrating but not harmful. Sometimes we might even choose to push ourselves, willing to have a temporary increase in our symptoms in order to do something that really matters.

Pacing does not always involve doing less. Sometimes people discover that they need to do more of an activity or approach something differently. It may be helpful to ask yourself the questions:

What is going to work for me right now?

Will I still be able to do other things that are meaningful to me later?

Adaptions and Equipment

We all approach energy management in different ways and one option is to consider if there are different ways to adapt day to day activities which may help you to maintain independence or reduce the energy demands you are experiencing. Below are just some examples, but please remember there is not a 'right' way of doing an activity and if it's important for you, for example, to iron your clothes then please prioritise this.

- **Laundry** Consider buying non-iron clothes, tumble dry so no need to iron, use a large plastic shopping bags with a zip top and roll it down the stairs (make sure its not too full), use trolley or laundry bag on wheels to transport washing around same floor level, use a combi washer/dryer, if you have no option to delegate carrying laundry upstairs try using a rucksack and bring a bit up at a time when using the stairs for other reasons.
- **Kitchen** Fill pans with water using a jug so no need to carry heavy pans full of water- use a stainless steel sieve in the pan so there is no need to lift the pan to drain the water. Think of your positioning could you sit down to prepare your meal? You might benefit from a perching stool. Try using ready chopped, peeled vegetables- fresh, frozen or tinned. Food processors can help with chopping (but will create more washing up). Use an electric tin openers or buy tins with built in pull rings. There are many countertop gadgets which can also help with energy management, including slow cookers (you can get liners to reduce washing up even further), Instant pots/air fryers, one cup kettles. Also look at where you keep things in your kitchen, is there a better position for them to be in to be more accessible and save energy?
- **Bathroom and personal care** If you are struggling to shower consider trying a shower stool/chair or a bath board (if shower is over bath), let your hair dry naturally or use a heated hair brush, use a hands free hair dryer holder, wrap hair in micro fibre hair wrap and sit in towelling dressing robe to reduce energy needed to get dry, dry shampoo, long handled sponges and shower foot scrubbers can be helpful, body dryers can be installed in bathrooms, consider a downstairs toilet or commode if struggling to access an upstairs toilet during the day.
- **Bedroom** Consider buying a lighter duvet to help with changing the bed, there are different techniques to change a duvet which avoids lifting, one is called the rolling technique, have a look on YouTube for further details. If you are struggling to get out of bed a bed leaver can be useful for some, however they do have risks and there are different types for different beds so seek professional advice.
- **General cleaning** Consider getting a light weight hoover or robotic version, easy reachers are useful for picking things up when having difficulties bending down.
- **Getting Out and About** There are many mobility aids available, speak to your GP who can refer you to your local community therapy team who can provide a full mobility assessment. The most commonly used include walking sticks, rollators with a seat in the middle which allows you to rest at any time, wheelchairs and mobility scooters.

Be aware that some mobility aids can increase energy demands such as a self-propelling wheelchair or crutches. If you are considering getting a wheelchair for day trips, consider who is going to push you- are they in good health? Will it fit in your car? How will you get it in your car? Where would a scooter or wheelchair be stored? Many places, e.g. shopping centres have facilities to hire out scooters for the day, this maybe a good option to consider before purchasing one.

In terms of cars, consider if an automatic would enable you to stay more independent.

Your **local therapy team** may be able to provide small pieces of equipment, however this does vary between areas. The most useful equipment for people with ME/CFS include:

- Perching stool- as the seat is on a slight angle this helps to gain a better range of movement in the arms compared to a normal chair, particularly helpful in the kitchen and bathroom.
- Shower stool/chair
- Bath boards
- Bed leavers
- Commode
- Grab rails/ stair rails- rails can be helpful to gain access into your home, in the bathroom for toilet and bath transfers.

All equipment mentioned above can be self-purchased, however **we recommend that you gain a professional assessment to ensure it is suitable and safe to use in your environment**, for example many baths are not suitable for bath boards due to shape or ridge thickness.

Social care Occupational therapy departments support with housing adaptations, for example putting a downstairs toilet into a property, widening doors or building ramps for wheelchair access, stair lifts, kitchen and bathroom adaptations. After an assessment and recommendation for adaptation has been made, you can then apply for a disabled facilities grant which is means-tested. There is no financial contribution required for smaller pieces of equipment however an eligibility criterion will still apply. If you live in a local authority or housing association property, contact them directly to enquire regarding their procedure.

For further details please access your local social care website on:

Sheffield: [Equipment and adaptations for your home | Sheffield City Council](#)

Derbyshire: [Equipment to help you live at home - Derbyshire County Council](#)

Doncaster: [Occupational Therapy - City of Doncaster Council](#)

Rotherham: [Get help with home adaptations – Rotherham Metropolitan Borough Council](#)

If you require a wheelchair assessment, please ask your GP for a referral to your local **wheelchair services**. Please note they do not provide motorised wheelchairs for outdoor use only. The main option is buying or hiring a mobility scooter if you do not have a suitable person to push you in a wheelchair.

For further information and advice regarding products and equipment, there is an online self help guide called AskSARA which was created by Occupational Therapists please go to [Disabled Living Foundation - AskSARA \(livingmadeeasy.org.uk\)](#)

With all equipment, self-purchased or provided by NHS/social care it is very important that you comply with weight limits which will be clearly displayed on the piece of equipment to ensure your safety.

Quality Rest

Physiological and Psychological Responses to Rest

Most people believe that rest is an important function both for our physical and mental health. It can be helpful to consider what happens in the body and brain when we rest. There is plenty of evidence that quality rest promotes our natural physiological regulation responses in many ways:

Cardiovascular:	Lowers heart rate and blood pressure.
Respiratory:	Lowers respiratory rate.
Musculoskeletal:	Reduces muscle tension.
Neurological:	Activates parasympathetic nervous system, inhibits sympathetic.
Endocrine:	Hormones which regulate physiological and emotional responses.
Digestive	Stimulates digestion.
Cognitive:	Improves cognitive processing.
Immune:	Activates repair and growth.
Sleep:	Rest does not reduce our ability to sleep at night.

Pretty amazing!!! What's more there are no negative physiological side effects associated with rest. No medication exists that is able to achieve these responses in the body. If we want to access these benefits we need to prioritise quality rest in our daily activity.

But...rest is not something we automatically do, it is not something we are routinely taught or that is practised widely in our society. It is normal to feel that you don't know how to rest.

Often when we think about rest we tend to focus on physical rest, for example watching TV, reading a book or browsing the internet may be considered 'rest', but mental activity is energy demanding and can drain our energy levels.

Tips for QUALITY rest

- Quality rest is regular and planned, not forced.
- Involves taking a break from physical, social and mental activities.
- Consider how you can minimise sensory stimulation when you rest.
- Quality rest is skill that requires commitment and practice. It can help to use directed relaxation techniques when developing this skill.
- Little and often, you may wish to start with short practices 5 mins.
- Rest is different from sleep, you may wish to set an alarm or sit rather than lie down if you think you are likely to fall asleep when you rest.
- It can be helpful to do something after your rest to get going again, e.g. some gentle stretches/fresh air.

Due to the physiological effects of rest you may find it helpful to consider rest as a prescription; you are experimenting with the dose, frequency and type of rest that works best for you.

Challenges to pacing and rest.

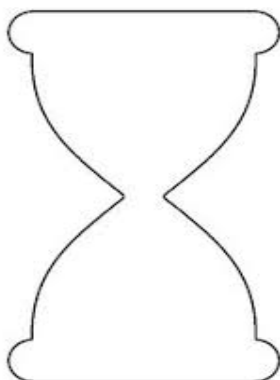
Pacing is difficult, knowing what to do and doing it are two very different things! Many of the barriers to pacing activities are related to our thoughts and link to our emotions. These thoughts play an important role in influencing our behaviour, making it challenging to use pacing and planned rest in practice.

Thoughts about PACING	Alternative suggestions
"I have to finish what I start"	It can be difficult to stop an activity in progress, but pushing through reinforces the 'boom / bust' pattern. Pacing tasks out over the day or week, may allow you to get more done overall.
"I can't pace everything"	It is impossible to pace everything all the time. Start with activities that are easier to control e.g. taking entitled work breaks, household tasks.
" I stop when my symptoms get worse"	If you rely on your symptoms to force you to stop it is likely to flare up of your symptoms and delay your recovery.
" I have to push myself because there is so much to do and no-one else is going to do it"	If you choose to prioritise self-management of your ME/CFS it does means doing things differently: Is it a priority that it's done today? Can someone else do it? Plan when to do it and how consider how you can pace the task.
"Other people will think badly of me if I do less"	Often other people don't see or know the impact of pushing yourself. Consider telling them why you are pacing. Pacing may involve challenging your rules about doing things in a certain way, relaxing your standards a bit and sometimes saying 'no' to demands.
"I have stopped doing activities I enjoy"	Incorporating pleasurable activities is an important aid to recovery. Engaging with pleasurable activities stimulate areas of the brain associated with soothing the body and mind. Consider how you can reintroduce or maintain an activity you enjoy on a regular basis.
"Will I have to stay at a reduced level forever?"	Once your energy levels are a little bit more stable you can start to gradually increase your baselines.

Thoughts about REST	Alternative Thought
Resting is a waste of time	Quality rest has been shown to have real physiological and psychological responses and is essential for recovery. Does this seem like a waste of time?
If I rest I feel like I'm giving in to the condition.	If you only rest when you have to then the fatigue is in control. By choosing to take regular, planned and limited rests you take back some control.
If I rest I'll fall asleep and it is hard to get going again	Try keeping rests short and if you are likely to fall asleep try relaxing in a chair rather than on a bed. Plan to do something stimulating after a rest; brush your teeth, get some fresh air, try some gentle stretches.
I only rest if I have to	Pushing ourselves, will mean it takes longer to recover. Our body functions more effectively with regular, planned rests.
I never used to rest	You didn't have ME/CFS.
Other people will think I'm lazy	How will others ever understand your needs if they never see the consequences.
Resting makes me feel worse	Resting too much can result in deconditioning, which means our bodies become even less efficient and fatigue more easily. Small amounts of activity combined with small amounts of quality rest can help recover energy levels.

Mindfulness practice: Breathing Space

This is a really useful way to bring a mindful pause into everyday life. It is simply a pause in activity, where you stop 'doing' and simply 'be'. There are 3 steps to the practice and you may like to spend a minute on each step but you can spend more or less time. This practice can be a helpful way to interrupt any tendencies to operate on 'autopilot' and can help you make choices about how to approach activities throughout the day. Initially some people find it helpful to set a reminder to do this at regular intervals.



Step 1 Awareness:

How do I feel in this moment? Notice sensations, thoughts, and emotions.

Step 2 Gathering:

Focus attention on sensation of the breath in the body.

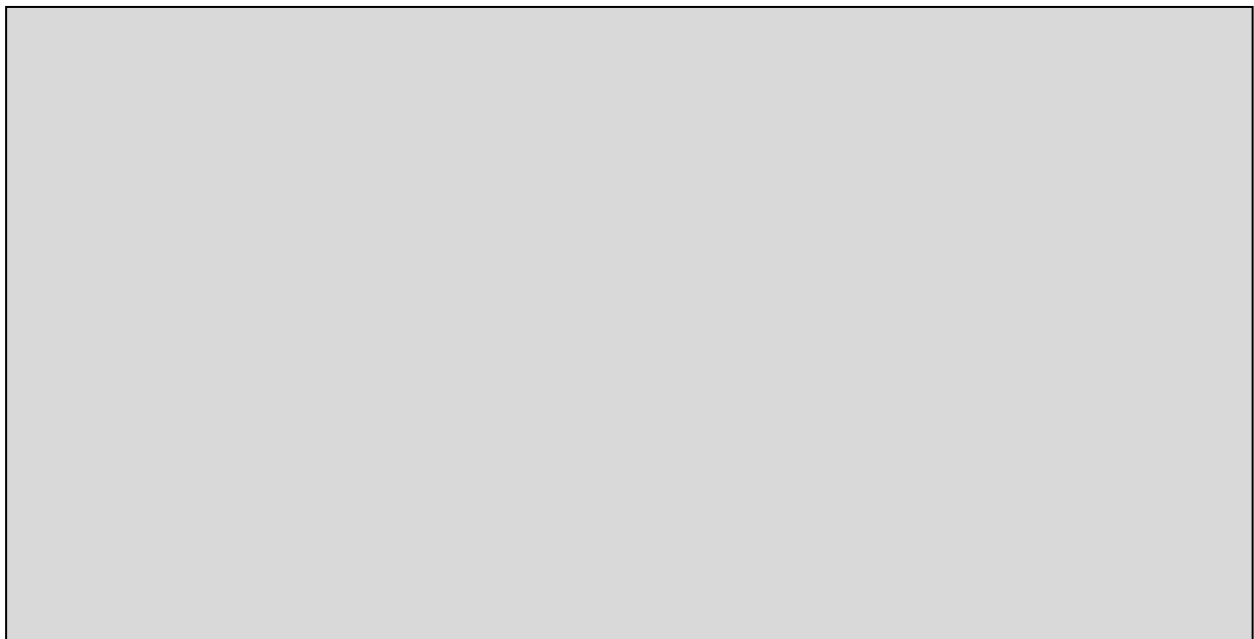
Step 3 Expansion:

Expand your attention to what is around you and a wider perspective.

Session 2: Home practice suggestions

1. Reflect back on the value based goal(s) you set last session. How did you get on? Did you experience any challenges?
2. Consider an action you can take in line with your value before the next session.
3. Consider how you might proactively apply pacing strategies. Have a go.....
4. Consider how you might proactively apply quality rest strategies. Have a go....
5. Complete 'Breathing Space' practice daily.

Session 2: Notes



SESSION 3

ME/CFS and Physical Activity

Physical Activity/Stress and ME/CFS

People with CFS/ME demonstrate an altered physiological response to physical stress. This helps to understand the experience of '**post exertional malaise**' (PEM). This is when an increase in physical activity or physical stress leads to a disproportionate increase in symptoms of fatigue and often includes widespread muscle ache. This response is typically delayed by a few hours up to 24 hours and prolonged, from a few days to a week and possibly longer. The experience of PEM is a key feature of ME/CFS.

The research indicates that ME/CFS may affect the way that cells produce energy in the body in response to physical stress. In addition the body's inflammatory response to physical stress may be altered in individuals with ME/CFS and the sensitivity of the nervous system to inflammatory chemicals heightened.

Secondary effects of physical deconditioning

The symptoms of ME/CFS may force a person to rest, initially resting may give some degree of relief but when rest is continued over a prolonged period with irregular bouts of activity changes occur in the body known as 'Physical Deconditioning'. This may add to the level of symptoms experienced. Physical deconditioning is a common secondary effect of living with ME/CFS.

Consequences of Physical Inactivity	Benefits of Physical Activity
Muscle weakness	Strengthens muscle
Stiff joint	Improves flexible
Reduced stamina/fitness associated nausea, dizziness, palpitations, shortness of breath	Improves heart and lung health
Poor temperature control associated cold peripheries, excessive sweating, hot flushes	Improved circulation and health of nervous system
Increased pain due to increased sensitivity of nervous system, may also lead to reduced coordination and fine motor skills	Improved health and mobility of the nervous system helps normalise sensitivity and proprioception. Production of natural pain killers, endorphins
Sluggish digestion, constipation / diarrhoea	Improved digestive motility
Disturbed body clock	Improved sleep patterns
Weight changes and appetite	Improves weight management improves appetite
Dulling of cognitive function, e.g. memory and concentration	Improves cognitive function
Lowers mood and increases stress	Improves mood, sense of achievement, social/fun. Promotes endorphin production, sense of well-being. Mops up adrenalin – stress hormones.
Muscle tension	Tension in muscles reduces
Increased risk of a range of health conditions eg, heart disease, stroke, diabetes	Improved long term health.

The body needs a level of physical activity to function well, it adapts to what is being asked of it. If we do less the body will become less fit. If we continue doing about the same, your fitness will remain constant. To get fitter you need to be regularly doing just a bit more however If you do too much more it will result in an increase in symptoms.

Getting fitter does not mean you have to start jogging or exercise in a gym. It involves responding flexibly, adjusting physical activity levels as required. Doing a small amount regularly and building up gradually at times when your symptoms are more stable.

An Individual Approach

The advice given here needs to be adapted to where you are in managing your ME/CFS. Some people will be doing too much physical activity and need to bring their activity level down to a more realistic and consistent level that relates to their present state. Others will be doing very little and may find it helpful to introduce a small amount of very gentle activity.

It is important to consider how you approach physical activity, pushing and striving is likely to maintain or flare your symptoms of fatigue. The key principles for approaching physical activity with ME/CFS are that it is;

Sustainable: At a level that can be undertaken (ideally) daily without a major flare up of symptoms.

Flexible: Levels of activity are planned in response to current symptoms and not exceeded. Consider pacing strategies.

Incremental: Increases in activity level should be small, introduced gradually, monitored prior to further increases.

Getting started...

Perhaps the most difficult aspect of managing physical activity is to come to terms with a starting amount, which may be considerably lower than you would like it to be. Using the activity diary may help you develop a better understanding of your current physical activity levels. Consider your present levels of fitness and how physically active you are in an average day. This might include walking, housework, DIY tasks, gardening, and physical demands of work or childcare. It is important to be realistic about how active you are so that you approach physical activity in a way and at a level that is right for you as you are now.

Some people find a structured programme can be helpful in building fitness in a careful, controlled way, allowing you to monitor your progress. Other people prefer a less formal approach. It is important to consider what approach is most helpful for you.

Identifying a physical activity baseline can be helpful. This is the amount of an activity you can do on daily basis without increasing symptoms. This may be quite low initially, finding the right amount to do is a matter of trial and error and it may take a week or two to establish. 50% of the amount that either brings on your fatigue or when you notice a change in the quality of your movement is often a good starting point.

It may be helpful to find a regular time of day that you can do some gentle physical activity. Use your Activity Diary to help you decide a time of the day when your energy levels are not at their lowest. Over a period of time if we exercise at a regular time of day our bodies adjust and prepare the body for an increase in physical stress.

If you are having a flare-up of symptoms it may be necessary to stop, reduce or spread your physical activity baseline for a few days or weeks. Many people report doing a small amount of gentle physical activity, even on a bad day actually helps them feel better.

Mindfully Connecting with the Body.

When our bodies are fatigued and possibly painful we may want to avoid giving them attention or we may even start to dislike our bodies. It is quite common when experiencing fatigue to feel frustrated or upset with our bodies' perhaps feel they are letting us down, or fearful of increasing our symptoms. These feelings can lead us to pushing the body or avoiding physical activity altogether. We may find ourselves feeling quite disconnected from our body and ignoring important information it may be giving us such as needing a rest, or needing to stretch and move.

What happens in the body affects what goes on in the mind and what goes on in the mind affects the body. By changing our relationship to our body, starting to really pay attention with kindness and gentleness we stimulates the calming aspect of the nervous system which in turn has a powerful impact on physical and mental health. One of the ways we can connect with the body through physical activity is mindful movement.

Mindfulness Practice: Mindful Movement

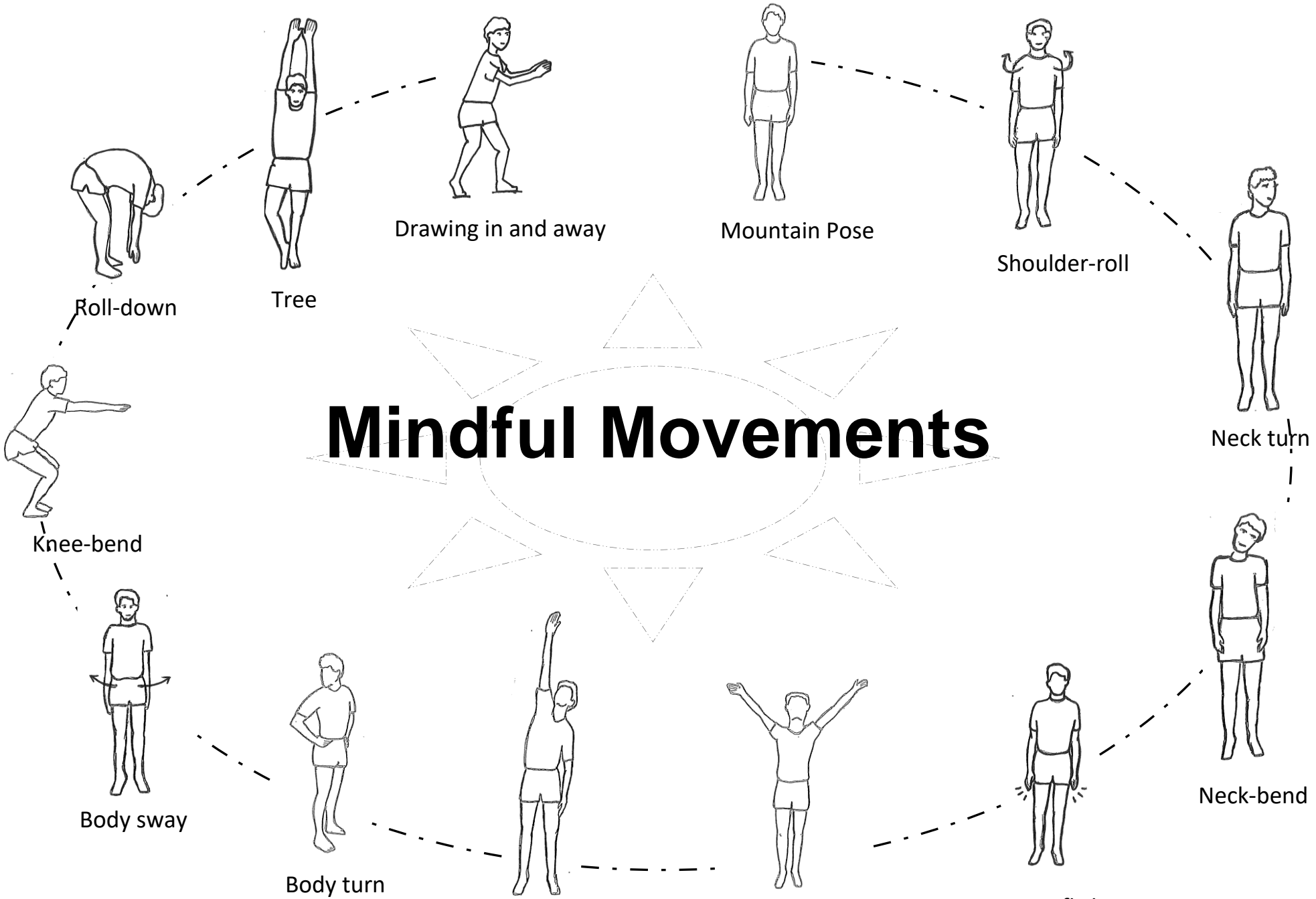
These movements are designed to allow us to gently reconnect with our body and tune in to sensations within the body through movement. Notice if you have a tendency to push or if you tend to be guarded. With this awareness you might chose to approach the movements a little differently.

- Only move within your capabilities, do not push into pain.
- Adapt any of the movements to suit your ability today; you may do the movements standing, sitting or lying down.
- When moving into a position, be aware of the physical sensations in your body
- Try not to hold your breath! You may wish to experiment with breathing into sensations of stretch or breathing out with the movement.
- Notice your thoughts during the movements. You may have striving thoughts encouraging you to do more which may lead to you over do it. Alternatively you might find yourself worrying about some of the sensations in your body and therefore hold back on moving the body freely.

Mindfulness Practice: Body scan

In this practice we bring our attention to all parts of the body, noticing the range of sensations present in our bodies at this moment. We also may notice our thoughts about these different sensations. If we find exploring an area of the body difficult we can choose to focus our attention on the sensation of the breath and return our attention to the next area as we move through the body.

Mindful Movements



Roll-down

Tree

Drawing in and away

Mountain Pose

Shoulder-roll

Neck turn

Knee-bend

Body sway

Body turn

Arm-reach

Hug and reach

Finger flicking

Neck-bend

Challenges you may encounter and suggestions of what might help

Challenges	Suggestions
Increased fatigue	<p>Are you doing more on a good day?</p> <p>Are you pushing yourself to get better quicker?</p> <p>Could you reduce, or split your baseline</p> <p>Are you prioritising other activities?</p> <p>Are there other factors influencing your levels of fatigue, e.g. stress, illness etc...</p>
Stopped doing exercises due to lack of motivation	<p>Get friends or family involved</p> <p>Have a regular slot</p> <p>Put up a reminder in a place where you will see it</p> <p>Try exercising with music, online, youtube</p> <p>Mix different forms of exercise to keep it interesting</p> <p>Consider joining a group activity, e.g. walking, tai chi class etc...</p> <p>Plan a reward</p> <p>Don't wait to feel motivated, JUST DO IT.</p>
Seem to have reached a ceiling	<p>Check out how much you are doing overall, you may have continued to increase your daily level of activities without realising it.</p> <p>Try reducing your baseline for a while and then increase more slowly</p>
Lack of time / Other obligations	<p>Are you prioritising physical activity.</p> <p>Is it in line with your values?</p> <p>Try planning a regular time slot. Trial different times of the day.</p>
Fear of increase in symptoms	<p>Give it a chance, it can take a little while but after 2-3 weeks most people find a small amount of physical activity improves energy levels.</p> <p>A short temporary increase in symptoms is not harmful.</p>

For your whole body to stay healthy you may wish to incorporate elements into your physical activity:

Stretching	Improves suppleness and flexibility of joints and muscles
Strengthening	Builds power and endurance in muscle, improves balance
Stamina	Increases tolerance to exercise and heart and lung health
Weight bearing	Maintains bone health

Understanding Pain

Many people with ME/CFS report persistent pain. Pain is complex but we have learned a lot of new information about it in recent years. Having some understanding of how pain works and how we can influence it can be helpful if you are living with persistent pain.

Pain is automatic protective survival process; it acts as a warning and involves lots of different systems in the body. We experience pain when the brain perceives there is a threat. The brain receives information from the body, the environment and our mind, factors such as past experiences, thoughts, beliefs and emotional state. The brain processes and interprets all this information to produce an experience of pain. This all happens subconsciously, within in a split second.

Different types of pain

Acute Pain Is usually associated with damage or possible damage to the body. It settles as your body heals, normally within 3-4 months. This pain is useful.

Persistent Pain Lasts more than 4 months and does not indicate on going damage to the body and therefore not useful. It may develop following an injury or for no apparent reason. Persistent pain is less to do with injury in our bodies and more to do with changes in the nervous system.

Persistent Pain and ‘Central Sensitisation’

The brain is the centre of the nervous system. Nerves connect the brain and body via the spinal cord. Nerves send electrical-chemical messages between the brain and body. In persistent pain the brain, spinal cord and nerves become more sensitive, this is called ‘Central Sensitisation’. Chemical changes in the nerves and spinal cord mean messages are sent to the brain, even in the absence of danger.

Common features of ‘central sensitisation’ are persisting, fluctuating, worsening, unpredictable pain that can spread over time. Movements, even small ones, can be painful and sensitivity to even light touch can develop.

With central sensitisation the brain is being told there is more danger at the tissues than there actually is. In response the brain sends messages to the body to protect from perceived danger. This causes changes in several body systems, for example muscle spasm, altered breathing pattern, chemical changes.

These changes wind the nervous system up even more. Over time the brain also adapts becoming more efficient at sensing pain. The brain ‘protects’ you by making the painful part more difficult to move or by making nearby body parts sensitive too.

Amazingly the brain can make connections between pain and other things such as certain movements, activities or environments. Sometimes just thinking about a movement can make pain feel worse.

The way we experience pain is highly influenced by our overall well-being. The natural chemicals connected with fatigue, stress, anxiety and depression are very similar to the chemicals used to communicate pain. In a sensitised nervous system these chemicals turn up the volume on pain.

Can Persistent Pain improve?

Yes, absolutely. Our nervous system is constantly changing in response to our experiences and we can positively influence and help to desensitise it. Learning about pain and gradually moving the body is one of the first steps. Equally important is taking a whole-person approach to your general wellbeing and life. Part of this involves doing things you enjoy, taking care of yourself and working towards goals which are meaningful to you.

Think about what influences your pain.

What makes it feel worse?

What makes it feel better?

The table below includes things that can influence persistent pain, either winding up or soothing and calming it. Understanding this can help you make informed choices about how you respond and help you to cope better.

Things that may wind up pain experience	Things that may calm the pain experience
Stress	Relaxation practices. Mindfulness practices.
Low mood	Regular gentle physical activity has been demonstrated to lift mood. Fully engage in pleasurable activities
Muscle tension	Regular gentle physical activity can relieve stiffness, help desensitise the nervous system and promote production of 'endorphins', the body's natural painkiller. Laughter reduces muscle tension.
Focusing on pain	Notice when thoughts are focused on pain. Prioritise and fully engage in pleasurable activities Focus on your immediate environment and your values. Meet up with or contact a friend. Introduce other sensations such as warmth, gentle massage a cool fan.
Fear of pain	Be reassured you are causing no damage: Hurt does not mean harm.
Pushing or avoiding activities	Prioritise, plan and pace.
Over stimulation	Pace exposure to stimulating activities, environments.

Pain Medication

Some individuals with ME/CFS have increased sensitivity to medication which may mean they experience more undesirable side effects. It is important to evaluate your personal experience of medication realistically. Medication may reduce your pain, helping you to get on with your life. Medication can't cure persistent pain or remove it entirely or permanently. If you wish discuss pain medications further please speak to your clinician.

Session 3 Home practice suggestions

1. Reflect back on the value based goal(s) you set last session. How did you get on? Did you experience any challenges?
2. Consider an action you can take in line with your value before the next session.
3. Review your Activity Diary, consider how you might pace your physical activities differently.
4. Have a go at doing the 'mindful movements'. You may wish to write down what you notice.
5. Consider what things may calm your pain response. Have a go....
6. Complete 'Awareness of breath' or 'Breathing Space' practice daily.
7. Have a go with the 'Body Scan' practice. You may wish to write down what you notice.

Session 3 Notes:

SESSION 4

Mental Activity / Cognitive Processing and ME/CFS

ME/CFS typically affects both physical and mental function. Mental activity includes cognitive processes such as thinking, concentrating and short term memory. These processes are energy demanding so it is not surprising that people with ME/CFS often experience mental fatigue; which can lead to difficulties with concentration and short term memory.

Difficulties with cognitive processes may lead to concerns that the brain is deteriorating similar to dementia or Alzheimer's disease. This can be very frightening, however we know that ME/CFS is a condition that affects the brain's function NOT it's structure, whilst Dementia and Alzheimer's are progressive disease processes affecting the structure of the brain. An analogy that can be helpful is to consider the brain as a computer. Dementia and Alzheimer's are diseases affect the computer's hardware whilst CFS/ME is a dysfunction of the computer's software.

Concentration

Concentration is the ability to focus our attention in the direction we choose. Our brain is constantly being bombarded with information from the body and the world around us. The brain filters this information so that we can focus and concentrate on what is important and relevant to us. In ME/CFS the filtering process is affected, so it is difficult to concentrate. Our ability to concentrate can be affected by several factors such as:

Physical and emotional state	When rested, relaxed and comfortable we tend to be calm; this makes us better able to concentrate. When we are distressed this interferes with our ability to concentrate.
Commitment	If we are not invested in an activity, it is difficult to sustain our concentration.
Enthusiasm	If we are interested or enjoy something it is easier to concentrate.
Skill	If we are confident with a task we don't worry about it, it is less energy demanding. Learning new skills and having new experiences may be more challenging.
Environment	There are lots of external factors can affect our ability to concentrate e.g. noise, temp, light, comfort, people.

Memory

Short term memory only lasts a few seconds and has limited capacity. For example to make sense of this sentence you need to hold the beginning in mind as you read the rest. However it is normal that you cannot recall the first sentence on the page. The more stimuli in the environment, sensations in the body and activity in the mind, the more difficult it is for our brains to filter out extra information AND the more difficult it is for our brains to recall information that has been stored.

Consolidation of memories into our long term memory occurs during the short wave sleep cycle. If this part of the sleep cycle is disturbed, for example by the stress response, we may have difficulties recalling this information. The ability to recall long term memories from the

brain is not typically so affected in CFS/ME. Long term memory can last for days, weeks or even a lifetime.

Self-Management Strategies

Practising mindfulness can help us develop our ability to focus our attention, this in turn can help with other cognitive processes.

Realistic expectations

- It is not helpful to compare your current abilities to your pre CFS/ME status.
- Most people can only concentrate for 20 mins
- Memory does naturally and normally reduce as we age.
- It is VERY common to overestimate or focus on our memory difficulties.

Activity management

- Consider baselines for mental tasks, remember to gradually grade up any increase.
- Apply pacing techniques to mental activities; prioritise, plan and pace.
- Change activities regularly, swapping from mental and physical tasks.
- Avoid multi-tasking, focus one thing at a time.

Environmental considerations

- How can you influence or adapt to noise, light, temperature.
- How can you reduce other distractions, stimulus?
- Are there times of day when your energy levels usually dip lower?
- Consider a reading window, adjusting font on screen text.

Memory aids

- Lists/Notebooks/Post it notes
- Prioritise – What needs to be done first?
- Smart phone/Diaries/Calendars
- Rehearse and repeat information either out loud, in your head or in writing
- Have a specific place where you return things to.

Internal Techniques

- Coding – linking objects to other meaning/descriptions.
- Chunking – for example a mobile phone number 07756341487 is easier to remember as 077-563-414-87. Or items on a shopping list into dairy, fruit and veg, freezer.
- Visual – patterns rather than numbers on a keypad. For example cash point.

Understanding and Managing Emotional Stress

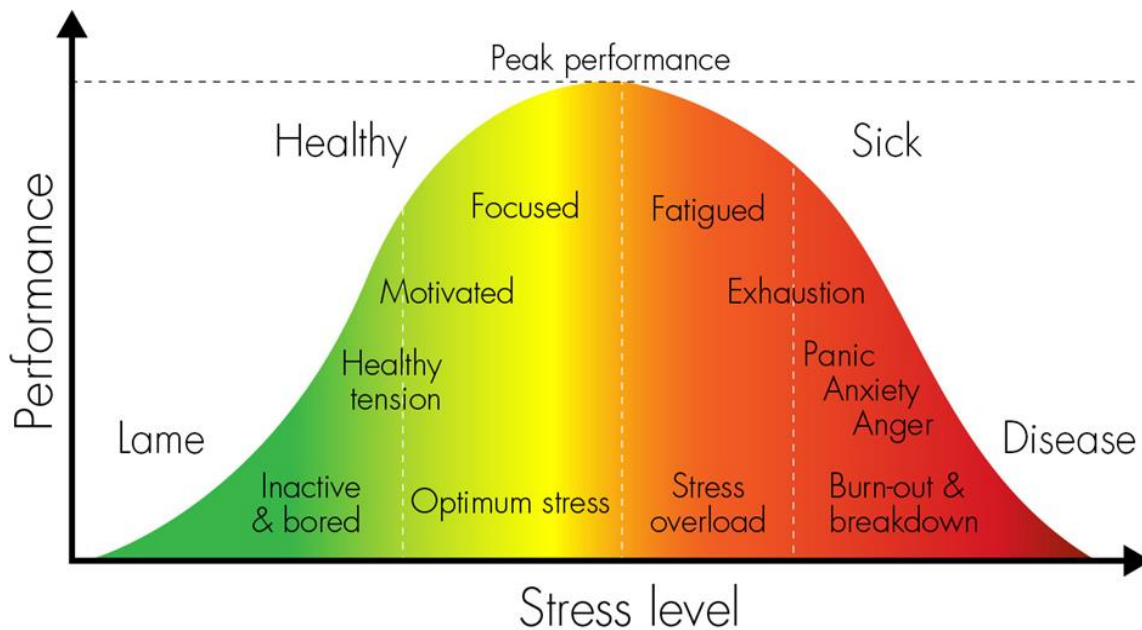
What is stress

We experience emotional stress when the demands on us exceed our current resources to meet those demands. Demands may include others expectations of us and our expectations of ourselves. Our resources refer to our energy levels, support available, coping skills and time.

Often when we think about stress we consider major life events such as bereavements, loss of work, relationship breakdowns or world events such as global pandemics, terrorism and climate change. Stress can be both 'positive' e.g. a new job, a baby, moving home and 'negative' e.g. loss of work, bereavement, difficult neighbours.

However stress often tends to be more frequent and persistent. It can be triggered throughout day by a range of situations e.g. getting stuck in traffic, feeling criticised by others, work and home demands, relationships and living with a long term health condition. This can result in a low-grade continuous stress response.

A certain level of stress is helpful to motivate us. Being overstressed however, means that we are less likely to enjoy ourselves, be efficient in what we do or think clearly. Being overstressed means we are using up a lot of energy and we can become more fatigued.

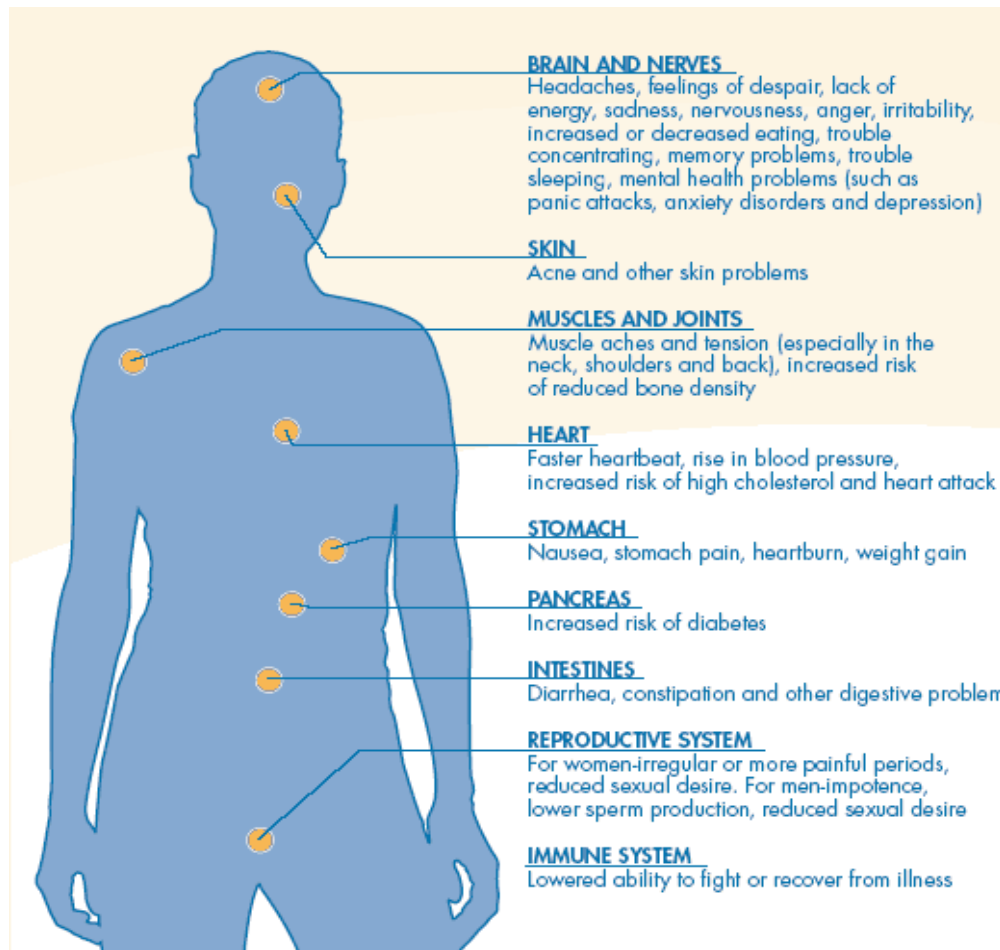


When we experience stress our bodies have an automatic physiological response, this stress response is a natural mechanism of the body to deal with a perceived or actual threat, it is a primitive survival response known as the 'fight or flight response'. It is intended to be short term response to get us out of trouble and it works well in many situations when we are under threat, e.g. a car coming towards us.

Let's consider the way our bodies respond to stress both in the short term and the long term.

The SHORT term impacts of stress

The body prepares itself for perceived threat by increasing heart and breathing rates, blood is pumped to the muscles and brain, increasing blood pressure. Muscle tension develops and we sweat more. Other body functions are not essential in the fight or flight response and so their function reduces, e.g. digestion, healing, growth and repair.



The LONG term impacts of stress

The stress response uses a lot of energy and so increases levels of fatigue. Although our bodies can respond to and deal with stress in the short-term, long-term continued exposure to stress can have negative effects on our physical and mental health, such as: Heart conditions, high blood pressure, increased risk of heart attack and stroke, asthma, irritable bowel syndrome, stomach ulcers, constipation, diabetes, reduced fertility, migraine, headaches, muscle spasm, fatigue, depression and anxiety.

Thoughts and stress

As humans we have the ability to think, this is fantastic, it allows us to plan, imagine, create and develop, however our ability to think is also a common source of stress. We have the ability to worry about what might happen, negatively predict the future, over analyse situations and ruminate on things from the past.

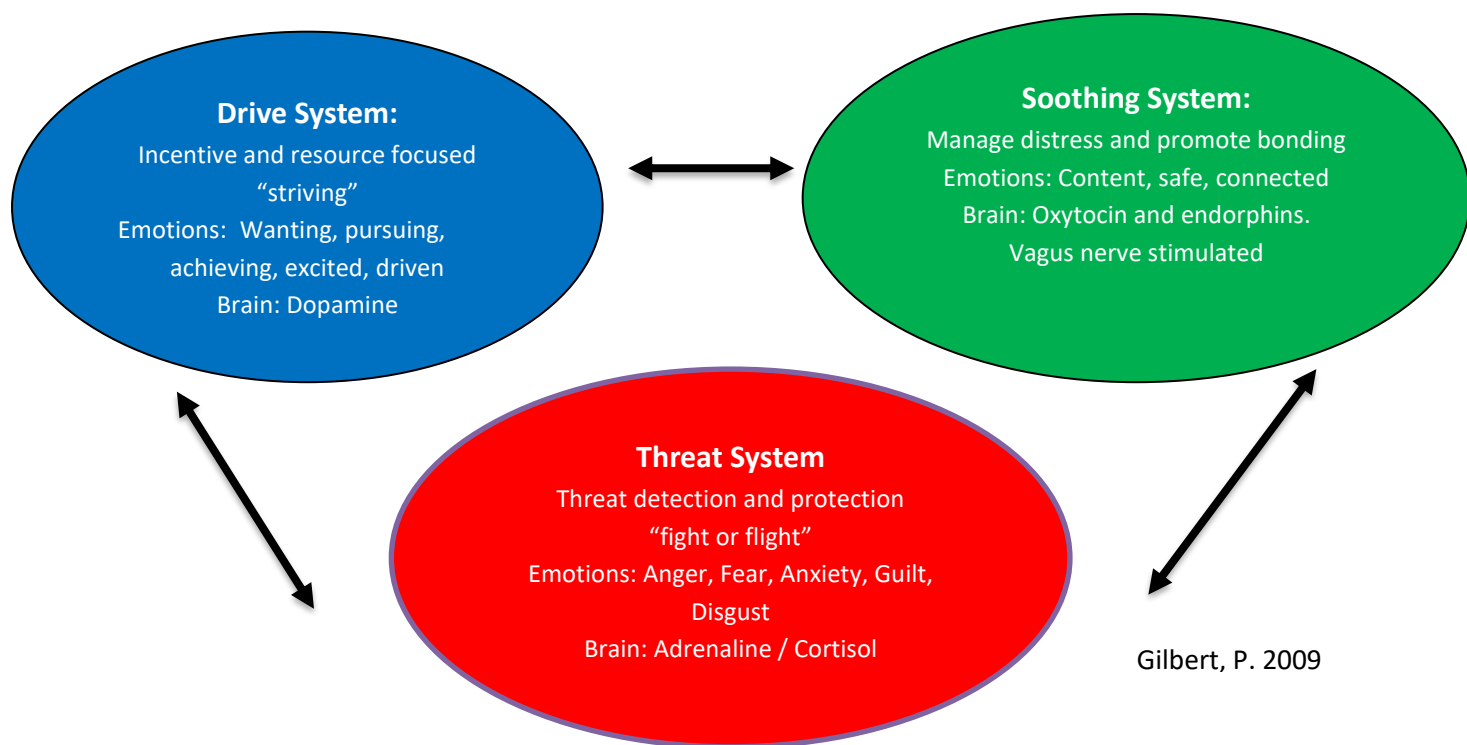
A lot of stress is triggered by our thoughts about perceived or potential threats e.g. 'I am useless' or 'they think I'm lazy' because we cannot do what we used to do. It is not a fault that the mind does this, it is an instinctive, protective, survival reaction but when continuously activated over a sustained period, other long term health problems can result.

This is why it is helpful to develop awareness of causes of stress in both our external world (e.g. work stress, relationships) and our internal world (e.g. thoughts/beliefs/assumptions). By being more aware of when our 'fight or flight' response is activated, we can have more choice in how we respond to stress.

Stress is a natural part of our lives and we may not be able to avoid or reduce the things that cause us stress. However we can work on how we respond to stress and make steps towards looking after ourselves in times of stress.

How do we manage our emotions?

Our brain has at least three major emotion-regulation systems. It's useful to learn about these systems so we can find ways to tap into the body's natural stress regulation processes.



Threat System / 'Fight or Flight'.

The threat system has evolved to protect us. The brain prioritises dealing with threat, focusing our attention to attend to it. When a Stone Age man was out gathering food and he encountered a lion, the threat system would ensure he reacted quickly e.g. ran or fought the lion. Our threat system responds the same way to threats we meet today. It will respond to both real (e.g. a life threatening situation) and perceived/potential threats (e.g. worries about the future, what other people think).

The brain tends to over-estimate threats and danger because it is designed to protect us and works on a 'better safe than sorry' principle. This means that unless we work at managing this system, our threat based emotions (e.g. anxiety, guilt, fear, anger) are easily activated.

Drive System / 'Striving'

The drive system has evolved to give us positive feelings that guide, motivate and encourage us to seek out things that we and those we care about need in order to survive and thrive. We are motivated by achieving things e.g. making nice food, finding a good place to live, enjoying friendships. When balanced with the other two systems, the drive system guides us towards important life goals.

Without any drive, we have little motivation, energy or desire. In contrast, if we have a lot of drive, it can lead us to push ourselves more and more, which can be overwhelming. When living with ME/CFS you may find yourself searching for answers or ways to get rid of or relief from the symptoms. When we can't get answers or symptom relief this can trigger the threat system and we may yo-yo between threat and drive systems.

Soothing System

The soothing system has evolved to allow us to feel safe, content and connected. It is vital to our sense of wellbeing and it plays a major role restoring balance to the other two systems. This system is largely governed by the hormone oxytocin and endorphins. When we are touched with kindness, or feel genuinely loved and needed, oxytocin is released. It creates a feeling of belonging, love and safety. This is complemented by endorphins, which act in a similar manner to opiates such as morphine. As well as acting as painkillers, endorphins also create feelings of calm, contentment and happiness. The vagus nerve is also stimulated which in turn activates the parasympathetic nervous system, important in calming the stress response in the body.

Behaving with self-compassion is very important to activate the soothing system.

Balancing the systems

All three emotional regulation systems are necessary for survival, optimum health and wellbeing. Problems arise when these three systems are out of balance which happens with prolonged illness or extended periods of stress. For example when the threat system becomes overactive we can flail around in fight or flight mode, desperately resisting our experiences and becoming increasingly frantic. If the drive system is overactive we may drive ourselves brutally hard and seek out distractions as we become increasingly stressed and depressed.

In this approach we are aiming to activate and develop your soothing system. There are many ways you might do this including doing gentle mindful movement, getting distance from difficult thoughts, doing things that are in line with your values and developing your self-care and compassion. The practice of mindfulness can be particularly beneficial, helping move us from our habitual 'doing mode' to the 'being mode' which can develop a sense of calmness, contentment and connection.

It is not possible to reduce the amount of stress we experience in some situations without changing the situation or our perspective of it. In order to manage stress effectively you need to be proactive and be prepared to make changes and adaptations to your lifestyle whilst maintaining a patient, realistic and step by step approach.

It is possible to develop and grow our soothing system by increasing the stimulation of this area of the brain.

Getting in touch with our senses.

Note down things you like to look at, listen to, smell, taste and touch.

Sight	Sound	Smell	Taste	Touch

As you do this notice how each of these pleasant experiences creates sensations in you your body, thoughts come to mind and feelings or emotions may arise.

e.g. When I hear birds singing, I think of spring, I feel calm and my body softens slightly.

Noticing the pleasant.

The mind is programmed to pay more attention to the difficult things in and around us. When we are suffering it's easy to lose sight of the fact that parts of our experience are pleasant so we may need to go searching for them.

The senses exercise highlights that there are many simple pleasures around us. Even on bad days there will be many micro-moments that can tilt the brain towards the pleasant. Doing this influences the hardwiring of the nervous system, nurturing and growing the soothe centre.

S ENSE Use your senses to be really present with the experience you are having.
E NRICH To enrich and enhance the experience stay with it for as long as possible.
A BSORB Take time to let it sink in, noticing subtle changes in the way the body feels.

Turning towards the unpleasant

It is human nature to resist difficult or painful experiences. Our natural reaction is to try and get rid of unpleasant things and seek out the pleasant. We might resist or avoid symptoms in many ways; trying to distract ourselves, or being in 'our head' not 'our body'. At other times we may feel overwhelmed by the unpleasant sensations as if they are the only thing in our experience.

When we aren't able to stop our symptoms, we can learn to relate to them differently. This involves allowing things to be as they are, letting go of trying to change our experience and making room for what is there. Whilst it may feel counterintuitive to turn towards the unpleasant in doing so we can gradually overcome our natural tendency to resist symptoms.

We can learn to respond in a way that will be helpful, not worsening our suffering. By opening up to unpleasant sensations and letting go of resistance it then allows us to more easily take in the pleasant aspects of our experience.

Strategies for managing stress

- Understand more about how stress affects you, recognise and accept your feelings
- Relaxation practices reverse some of the physiological responses to stress. Even short pauses, for a minute or two can have an impact.
- Maintain a healthy lifestyle by doing regular gentle physical activity, eating a healthy balanced diet, establishing a regular sleeping pattern, managing activity levels,
- Practice realistic goal setting.
- Make use of a good social support network by asking for help and/or accepting it when offered, talking to people, family and friends.
- Improve communication skills by being assertive and learn to say no.
- Make time for activities you enjoy, set aside time each day to do something you like.
- Recognise what is outside your circle of influence and beyond your ability to change.
- Adopt a problem solving approach to difficulties, identify different solutions, try one and evaluate it.
- Set aside time for reflection and reassessing your values. Review your goals realistically.
- Learn to identify unhelpful thoughts; these are likely to pop up when we experience stress.

Mindfulness Practice: Soothing Rhythm Breathing

Up until now we have mostly focused on the sensations of the breath just as we find them. There are other breathing rhythms that can be helpful. By lengthening the out breath for example we trigger the parasympathetic nervous system, having a soothing, more calming effect on the body and mind.

Session 4 Home practice suggestions

1. Reflect back on the value based goal(s) you set last session. How did you get on? Did you experience any challenges?
2. Consider an action you can take in line with your value before the next session.
3. Senses exercise – planning exposure to pleasant sensory experiences.
4. Review cognitive activity in your Activity Diary and consider how you may adapt your approach.
5. Review stress management strategies and experiment.
6. Daily Mindfulness Practice: Breathing Space / Soothing Rhythm Breathing
7. Regular mindful movement or other planned gentle physical activity.
8. Complete 'How is it going so far', pg 39.

Session 4 Notes:

How is it going so Far?

We are now over half way through the course. It can be useful at this point to reflect on what you have achieved so far and whether there is anything you would like to be doing differently.

What have you learnt from the course so far?

What have you achieved so far? – for instance are you doing anything differently ? or Have you taken any steps to live more to your values?

Are there any barriers or obstacles preventing you from getting as much out of the course as you would like?

What Next?

What would you still like to achieve on the course? Consider the steps you might need to take. If there are obstacles what might help?

SESSION 5

Thoughts and ME/CFS

Living with ME/CFS is not easy; the symptoms have a significant impact on all aspects of your life. As a human it is natural that you will have thoughts and attached emotions about ME/CFS and its effects. These thoughts influence all aspects of the experience of living with ME/CFS. The way you think about your symptoms is likely to change depending on how they are, and what is going on in your life at any time. You may be concerned about not being able to do activities which are expected of you, or what the future might hold. This can lead to many powerful emotions and drive your behavioural response in unhelpful ways; you may push through leading to more symptoms, or avoid activities that matter to you.

Psychological therapies including Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT) are used in a wide range of illnesses and health conditions. Some of these conditions could be considered psychological, such as anxiety and depression, whilst some are considered long term physical conditions such as diabetes, heart disease and chronic pain syndromes. Making use of psychological treatment approaches does NOT mean that ME/CFS is considered a psychological condition. Psychological therapies are not a cure ME/CFS, however they can be helpful when trying to adapt and be flexible with behavioural responses to symptoms.

ACT focuses on developing awareness of our thoughts as events that arise in the mind and also pass, learning to accept our thoughts in the knowledge they do not define us, choosing how to respond to our thoughts flexibly and take action in line with our values. ACT acknowledges that when we are not aware of our thoughts we can easily get caught up in a struggle, striving to solve the unsolvable, adding layers of distress to our experience.

What are thoughts?

Thoughts are automatic – we don't get to choose them. They evolve from our experiences, or are learned from our knowledge and understanding of the world we inhabit. Thoughts come together to form an internal monologue, a story, about how we see ourselves, others and the world. Our thoughts include many things: Ideas, opinions, judgements, memories, predictions, rules, beliefs, assumptions, criticisms. They are our personal interpretation of the world around us, the private internal commentary which helps us make sense of our experience, they are powerful drivers for both our behaviours and emotions.

It is human nature to categorise and we do this with our own thoughts, e.g. good/bad, right/wrong, positive/negative, however this is not very helpful as it does not necessarily take into account the context of our current situation. It may be more useful to consider if our thoughts are helping us to take actions which move us towards or away from our values.

Are thoughts facts?

Consider the following scenario; write down your thoughts, feelings and physical sensations:

You are walking down the street and on the other side of the street you see someone you know. You smile and wave, the person doesn't seem to notice you and walks by....

Thoughts	
Feelings	
Physical sensations	

It is likely that everyone will view the situation differently; because we have all had different life experiences and so will have our own interpretation of events. We may pick up on some things and miss others, and this can be affected by how we are feeling from moment to moment. Or we have an initial thought followed by another that may contradict or confirm our first thought. It is as if we are wearing lenses that filter our experience.

Thoughts are NOT facts!

Now consider how your thoughts may influence your experience of ME/CFS. Imagine waking up one morning with a flare up of your symptoms. What thoughts and emotions come up, is there any physical sensations in the body, how would you typically respond?

Thinking styles

We are creatures of habit; this applies to our behaviours but is also true of our thoughts. We tend to think in habitual ways and adopt styles of thinking. Becoming aware of our thoughts and thinking style can be very useful, as we can begin to review and appraise them fairly. This can in turn influence our behaviour in more helpful ways. Thinking styles are:

- Automatic They pop up without any conscious effort.
- Distorted Not usually entirely accurate.
- Plausible Believable.
- Durable Difficult to change.
- Persistent Hard to turn off.

Some commonly recognised thinking styles are listed below; do any resonate with you?

Thinking style	Description	Example
Catastrophic	Getting things out of proportion so things appear worse than they actually are.	My muscles ache. I must be doing some permanent damage to them.
All-or-Nothing Thinking	Looking at a situation as two extremes. There is no middle ground.	If I can't do it the way I used to I may as well not bother.
Emotional Reasoning	Taking as a feeling as a fact and dismissing evidence to the contrary.	I feel a complete failure = I am a complete failure.
Mind- Reading	Assuming others have negative thoughts, motives, or intentions about you without considering other possibilities.	They must think I am a fraud.

Fortune Telling	Negatively predicting what will happen in the future.	I will never feel any better.
Over-Generalising	Making the negative assumption that, because something has happened once, it will obviously happen again.	I felt awful when I increased my exercise so it is always bound to happen.
Labelling	Putting a 'fixed' or 'global' label on yourself or others without looking for contrary evidence.	I am useless.
'Should' and 'Must'	Fixed expectations of how you and others should behave.	I should/ must be able to do all of the chores in one go.
Disqualifying the positive	Paying attention only to negative aspects of a situation rather than seeing the whole picture.	I've hardly been able to cook for the family this week. I don't deserve to have a family.
Double Standards/putting yourself down	Treating other people in a different way to how you would treat yourself in that situation. Often we treat others with more compassion than we give ourselves.	I didn't finish everything I wanted to do. I must be useless (but it is OK for others not to finish everything).
Personalization	Believing that if somebody behaves in a negative way it must be because of you.	The man in the shop was a bit short with me. I must have offended him.

Because our thoughts are automatic, we are often unaware of them. It can be easier to notice when we feel a change in emotions; we may even notice physical signs of our emotions such as muscle tension or changes in our breathing. At this point we can consider what is the situation or event that has happened? What emotions are we feeling? What is the thought we are having? Does it fit a particular thinking style?

Working with thoughts

Passengers on the Bus Analogy

Imagine that you are the driver of a bus. The bus represents your life's journey, as the driver of the bus you get to choose the direction you travel (your values), the route you take, the destinations you visit (your goals) and how you drive. As you travel along the route of your life's journey you pick up various passengers. These passengers represent your thoughts, emotions, physical sensations and responses to the journey.

Some of the passengers are pleasant, many are neutral, but some passengers are horrible. They are loud, aggressive and threatening. They tell you you're a terrible driver. They warn you that you are going the wrong way. They threaten that if you do not turn around or take a detour your life will be awful. These passengers can be very scary to listen to and can really get us down.

Take a moment to consider what your different passengers might be in relation to your ME/CFS.: What are the most prominent? What do they say? What tone do they take? Make a note in the box below:

It can be tempting to stop the bus, or get into an argument with the passengers, or even try to throw them off the bus or stop them getting on; however, this is exhausting and results in not moving towards our value, getting stuck with and by our thoughts. What would it be like to acknowledge the passenger but continue to drive the bus anyway?

It is normal to get a bit stuck with certain thoughts, below are some suggestions for techniques to help get 'unstuck'. Remember it takes patience and practice.

Techniques for getting 'unstuck'

Notice and Observe Create some distance between you and your thought.

Try observing the thought; 'I'm having the thought that,', or even 'I notice I am having the thought that.....'

Mindfulness Practices Help us to notice the activity in our mind but not get caught up in the content. Rather than trying to suppress or ignore thoughts we learn to observe them as mental experiences which come and go. If you notice yourself going round in circles, pause and mindfully bring your attention back to the breath. This can help us to look at our thoughts rather than from them.

Visual techniques Put your thoughts on paper can help us to see them differently. It can give us an opportunity to pause and reflect on its meaning. Try holding the paper with your thoughts written on close to your face. Then place the paper in your lap look around, notice what you can see, hear, smell, touch and taste.

Experiment with drawing speech bubbles around them, be playful with doodles. If using a computer screen playing around with font style, size and colour, adding clip art, or a Karaoke screen with the ball bouncing over the words.

Auditory techniques Say your thought to yourself, in a silly voice, out loud or quietly, fast or slowly, sing it to yourself, try different tones of voice or accent. Notice how the experience changes.

Ask yourself?

- Is this thought helping me move towards my value or keeping me from it?
- Is this a thought or a fact?
- What would I say to a friend or loved one who had this thought?
- Am I blaming myself for something that isn't entirely my fault?
- Am I expecting too much of myself and putting myself down?
- A more helpful realistic alternative thought would be?

Communication

Often we use a lot of energy trying to please the people around us, trying to meet others expectations or what we think are their expectations are of us. Understanding our relationship with others and exploring how we communicate our needs effectively can help prioritise limited energy more efficiently.

Other people, including family, friends and work colleagues are often affected by the impact of your ME/CFS. Their understanding of your personal circumstances and the condition will vary enormously. Whilst you cannot control how other respond to you and the effects of CFS/ME on your life you can consider how you communicate with them and potentially influence their responses.

People with ME/CFS describe a range of difficulties related to communication:

- CFS/ME is invisible. Others can't necessarily see what we are experiencing.
- People get bored, forget or don't believe your situation? They stop trying to help, or even avoid you.
- Cognitive difficulties can make it difficult to articulate what we want to say.
- Being misunderstood, ignored, dismissed or given unhelpful advice by others.
- Feeling the need to justify the way you feel, validating the condition.
- Communicating can be stressful and energy demanding.

How do we communicate?

It is helpful to be aware of the different forms of communication. Our body language, tone of voice and the actual content of our words all communicate messages when we speak. The proportion of information given is:

Body language 70% Tone of voice 23% Content 7%

How do you communicate with others about your fatigue? Consider how your body language and behaviour relates to what you say and how you say it and the messages that it may send, how is it received? Does it match? Difficulties with communication can arise when we send out mixed messages. Is how you are communicating effective?

Communication Styles

The way we communicate with others can make a difference to the response they give. We all use different styles of communication at different times and in different situations. Consider these four commonly recognised styles of communication.

Each style looks and feels quite different both for the person communicating and the person receiving. Consider how effective and efficient each is in relation to energy management and getting your needs met.

Aggressive

Looks: Confrontational, invades personal space, staring, pointing.

Sounds: Raised voice, shouts, unable to negotiate.

Feels: Often leaves other person feeling devastated or defensive. Doesn't listen to or respect views of others. Over reacts and may resort to putting others down.

Impact: May get needs met in short term but in long term usually consequences. Associated with feelings of fear and frustration, Often linked with low self-esteem.

Passive

Looks: Submissive, limited eye contact

Sounds: Quiet, fails to express thoughts, feelings, beliefs and needs. Apologetic for situations beyond control.

Feels: Avoids confrontation at any cost, unclear what needs are. Avoids making decisions and blames others for feelings and actions, sees self as victim.

Impact: Needs remain unmet. Gives into others demands, compromising own needs. Associated with feelings of helplessness, often linked with low self-esteem.

Passive-Aggressive

Looks: Mismatch between words and body language. Eye rolling, silent treatment and door slamming. Talking to others rather than the person concerned.

Sounds: Sarcastic and or silent.

Feels: Guilt inducing, confusing. Messages unclear tend to hint at what they mean or agree and then backtrack. Manipulative, often contradictory and inconsistent.

Impact: Lack of honest opinion can lead to needs remaining unmet. Associated with difficulty regulating and expressing emotions, teenagers.

Assertive

Looks: Calm and confident, respectful of and actively listens to others. Body language, tone and content match.

Sounds: Clear, consistent message able to express thoughts, feelings and needs honestly.

Feels: Respectful and authentic, takes responsibility for actions and choices. Self-confidence is not shattered if requests refused

Impact: Able to negotiate and compromise flexibly without giving in.

Assertiveness Strategies

Assertive communication is the most energy efficient style of communication.

- Use of 'I' statements allows you take ownership of your feelings and behaviours; this means the other person is less likely to become defensive and the situation less confrontational. Be clear about: how you **feel**, what you **need**, **what you would like** the person to do. e.g:

'I am feeling upset because I can't do what I used to, I need more help around the house, I'd like you to do the shop at the weekend.' Rather than 'You've upset me, you don't help out around the house.'

- Plan ahead, what do you want to communicate, rehearse it if helpful, or write it down. Identify a good time for the conversation, when there is less distraction. Avoid starting difficult conversations late at night.
- Sometimes it is useful to ask for more time and delay a conversation or decision.
- Don't assume what others are thinking, ask. Don't assume others know what you are thinking tell them.
- Be calm and confident without being rude; try to repeat a clear, consistent message. Consider if your body language and tone of voice reflect what you want to say.
- Practise saying 'no' without apologising. You do not have to give elaborate reasons. You may wish to tell the person that you are finding things difficult, or what your needs are in relation to your self-management strategies.
- Be prepared to be flexible to achieve a working compromise. This may involve reviewing prioritisation of your demands.
- Remember to give positive feedback to people when they say or behave in a way that you find supportive or helpful.
- It may also be helpful to consider which relationships you choose to invest your energy in.

Listening Skills

Listening seems like a natural skill, yet it requires attention and practice to stay present and truly hear what another person is saying. The mind tends to wander, or we're planning our response so we may miss the core message.

Listening mindfully by paying attention to the speaker without interruption, without getting defensive, and without a need to always be right or make a point. To get the whole picture, we need to engage all of our senses and concentrate on the personal gestures and the messages that are being communicated. You may like to try the following:

- Allow the person to finish what they want to say rather than finishing their sentences
- Paraphrase back what you heard to clarify if that is what they meant.
- Take a mindful breath before responding. Pausing can work to our advantage.
- Listen to your intuition; notice your feelings, thoughts, and body sensations as they arise.
- Pay attention to the clues beyond the words (e.g. their tone and body language).
- Listen with a willingness to understand their point of view, even if you don't agree with it.

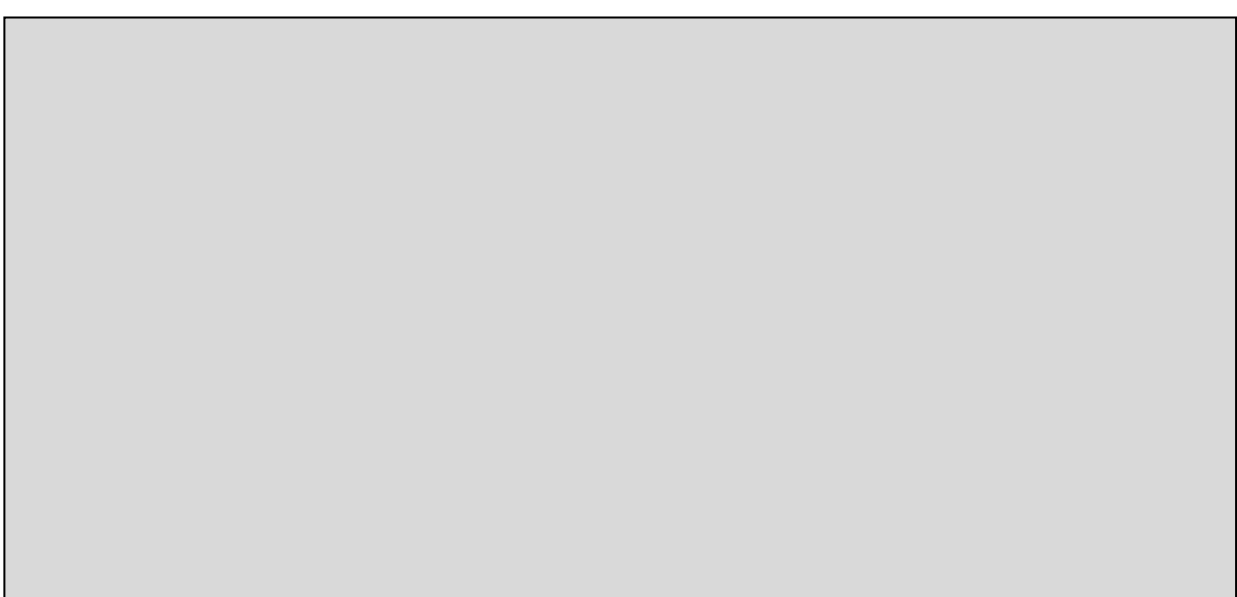
How we talk to ourselves....

Be aware of the internal conversations you have with yourself. We all have an internal self-critic. Notice how you speak to yourself, do you use a particular style of communication? Compare this conversation to how you would speak to others, consider how you would speak to those that you love and care about. Often we talk to ourselves in a much more critical voice, this is more energy demanding, Can you be more compassionate with yourself? How would it sound, what would you say?

Session 5 Home practice suggestions

1. Reflect back on the value based goal(s) you set last session. How did you get on? Did you experience any challenges?
2. Consider an action you can take in line with your value before the next session.
3. Consider your thinking styles and /or 'passengers', how might you respond to them, what action will you take?
4. Leaves on a stream mindfulness practice. Write down what you notice:
5. Consider your communication styles and any experiments you wish to try.
6. Daily mindfulness practice: breathing space or alternative mindfulness practice.
7. Mindful movements or other form of gentle physical activity.

Session 5 Notes



SESSION 6

Sleep and ME/CFS

Unrefreshing sleep is characteristic of ME/CFS. In addition people with ME/CFS often report their sleep patterns have changed, they may sleep much more than usual perhaps napping during the day or develop difficulty getting off to sleep or find that they wake up during the night. Occasionally sleep patterns may be reversed, sleeping in the day and awake at night.

It is widely accepted that sleep plays an important role in supporting:

- Cognitive function such as our ability to concentrate and our memory.
- Physical functions including growth, repair, healing.
- Mental health regulating mood.

Because we accept that sleep is important it is natural that we may become concerned if we experience changes to our sleep. It is common for people both with and without ME/CFS to overestimate their lack of sleep. Paradoxically the anxiety associated with these thoughts can exacerbate the problem.

Sleep is an automatic function of the body; it is governed by two things: **Sleep pressure**, the length of time since we last slept AND our Circadian rhythms, also known as our **Biological body clock**. Circadian rhythms are responsible for our waking / sleeping rhythm and are determined by complex interactions between our hormones and the environment. Melatonin, our sleep hormone, increases in the evenings when it gets dark. Individual variation in our body clocks can lead to some people being naturally 'morning larks', whilst others are 'night owls'.

Our circadian rhythms are set by cues and signals, if disturbed these rhythms can slip, for example the experience of 'jet lag'. This can result in difficulty sleeping at night and increased daytime fatigue. Sleeping in the day can reinforce this.

There is a broad range of 'normal' amount of sleep, between 4-7 hours of sleep is considered enough. Our needs change naturally over time; generally we need less as we age.

We sleep in cycles of approx 90mins, experiencing 4-5 cycles per night, each cycle has 5 stages:

- | | |
|-----------|---|
| Stage 1-2 | Light sleep, slowing of physical and mental activity, easily woken. |
| Stage 3-4 | Deep slow wave sleep, hard to wake. This part of our sleep is associated with memory, learning and vigilance.

Mental and physical function maintained and restored. The brain adjusts the amount of deep sleep to ensure this is caught up in the earlier sleep cycles. Stress before bed has been demonstrated to reduce slow wave sleep. |
| Stage 5 | Light REM, dreaming sleep. Thought content often bizarre or illogical, similar levels of brain activity as when awake, normal to experience muscle paralysis during REM. We all dream but we do not always remember our dreams. |

Barriers to sleep

Many things can get in the way of a good night's sleep, for example being uncomfortable or being distracted by our thoughts. Some of these we can act upon, some are out of our control. It can be helpful to consider our thoughts at these times; the mind can quickly create the story of "I'm not a good sleeper".

People often describe lying awake in bed worrying about not sleeping, distracting themselves on electronic devices, trying really hard to sleep, tossing and turning, checking the clock, allowing themselves to lie in the following morning, or nap during the day to make up sleep they have lost. These behaviours tend to reinforce disturbed sleep patterns.

Sleep strategies

Develop your bed/sleep connection

Time spent in bed awake disrupts the brain's association of the bed with sleep; weakening the "bed sleep connection". Avoid any activity in bed which does not involve sleep or sex.

Sleepy tired vs Fatigue.

Go to bed when you are sleepy/tired, not fatigued. Sleepy/Tiredness is when you are yawning, your eyelids are closing, and it's hard to stay awake, these are your cues. Sleepy/Tiredness is relieved by sleep, fatigue is not.

Consider your 'going to bed routine'

Consider how we establish a bed time routine for children. Avoid stimulating activities in the hours before bed. You may wish to avoid screen time before bed.

Regular wake and rise time.

Get up at the same time every day regardless of your night's sleep. This helps re-establish your sleep pressure and biological body clock.

Avoid daytime napping,

Napping can reduce sleep pressure for that night. However it is important to be flexible, if you are having a flare up or are ill a short nap may feel helpful. Try to limit to 20-30mins if possible. Feeling a need to nap may be a sign that you would benefit from more planned rests throughout the day.

15 minute strategy

If you are not asleep, get up, do something quiet or sit in a chair in another room and return when you feel tired again. This helps strengthen the bed/sleep connection

Relaxation

There is great evidence that relaxation practice promotes sleep. Progressive muscle relaxation is best evidenced in sleep studies. Relaxation provides the optimal environment in the body; reduced tension, slower deeper breathing patterns, warmth and distraction from thoughts. It can also strengthen the brain's association with preparing for sleep.

Practical adjustments

Consider practical adjustments to the room, mattress, bedding layers, fans, ventilation, curtains. Remove electrical devices such as televisions, clocks, computer, tablets and phones from the bedroom.

Medication

If you take pain medication modified release preparations can help to cover night time pain. A short course of sleeping tablets may be helpful to break a habit of not sleeping.

Worry time

You may wish to keep a pen and paper by your bed to note down any worries. Plan a regular time in the day to attend to the list; problem solve what you can and for the worries you cannot solve can you be self-compassionate, acknowledge this is an important worry, there is no simple solution.

If you are struggling to get off to sleep due to a racing mind you may wish to try the following techniques:

Visualisation technique

Think of a fruit that is easy to put into your mind in great detail, for example a banana. Think about it very carefully. Try to imagine the most perfect banana that you have ever seen, from the stalk all the way along the yellow lines, including the small dark marks. Once the picture is there in detail change the colour. Think of exactly the same piece of fruit, but as a blue colour. Again, take your time to make the image as detailed as possible, as it would be in a painting. Think about how the brown stalk may now look blackish. When it is clear in your mind change the colour again.

Verbal technique

Think about a category, for example countries or foods or animals. Don't pick anything that you are emotionally involved in. For example, a vet might not want to choose animals. If you are using countries, think of the first country that pops into your mind, for example Spain, and then think of another country that begins with the last letter of the first. Keep working through the sequence of words. It doesn't matter if you get them wrong and it doesn't matter if they are in any particular order. This is simply a way of creating a stream of words that doesn't have any particular emotion attached. It breaks the cycle of your mind fixing on any one thing.

You might also try going through the alphabet and thinking of a fruit or vegetable for each letter.

Number technique

Some people think in a more mathematical fashion. If you do then this technique may be worth trying. Start with the number 1000 and take away 7. Keep on going down, e.g. 1000, 9993, 9986 and so on. Again, it doesn't matter if you make a mistake, but just keep working through the number sequence.

Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS) is also called ME, which stands for myalgic encephalomyelitis, (or encephalopathy). CFS/ME affects both adults and children, and can be serious, causing long-term illness and disability.

What are the symptoms?

Symptoms include some, or all, of the following:

- constant, overwhelming mental and physical tiredness (exhaustion)
- sleep disturbance, un-refreshing sleep
- post-exertion malaise (feeling worse after exercise)
- muscle pain and/or weakness or joint pain
- headaches, poor concentration or poor memory recurring sore throats or 'flu-like' symptoms
- feeling sick, (nausea)
- symptoms of IBS (Irritable Bowel Syndrome), such as wind/bloating, stomach pain, diarrhoea and constipation
- intolerance, or sensitivity, to alcohol, caffeine, some foods or medications

CFS/ME is poorly understood, with no specific diagnostic test. Diagnosis is made by excluding other causes of the symptoms.

Can what I eat help CFS/ME?

Eating a variety of healthy foods is very important for your health and wellbeing. Although diet alone isn't the cause, or cure, of CFS/ME, a poorly-balanced diet can compromise your health. Use the Eatwell guide to ensure your diet contains the best balance of foods from each group.

- **Potatoes, bread, rice, pasta and other cereals**, especially wholegrain provide fibre and energy. Try to include low GI (Glycaemic Index) foods, such as oats and wholegrains, which slowly release energy, helping to keep your energy levels stable. Eat a portion at every meal. If you are less active, because of your ME/CFS symptoms, you will use fewer calories, so choose healthier types over those high in added sugars and fats.
- **Fruit and vegetables**. Aim to eat more- 5+ portions a day.



- **Beans, pulses, fish, meat, and eggs**. These provide protein. Eat two portions a day. Eat more pulses and beans, and fish, and less processed meat, such as ham, sausages and burgers. Nuts also provide a nutritious snack, or addition to a salad or cereal.
- **Dairy and alternatives**. An important source of calcium for good bone health. This includes milk, cheese, yoghurts and calcium-enriched milk alternatives, such as soya based products. Note: not all milk alternatives, particularly organic ones, are calcium-enriched.
- **Fluid**. It is important to have a good fluid intake, 6-8 mugs / glasses per day is a good goal. Having too little fluid can lead to headaches, constipation and reduced alertness. Any type of fluid such as squash, juice, water, tea and coffee all count towards this.

Eating a little and often may help your symptoms. For example, have three smaller meals daily, with the addition of three snacks in between.

Unwanted weight changes?

People with CFS/ME may put on weight because they are less physically active. They may also eat more, because of low mood, boredom, comfort eating, or wanting to boost energy levels. Some report feeling more hungry than usual, (polyphagia). To combat weight gain keep higher calorie, fat and sugar foods, such as biscuits, chocolate, cake, crisps and sugary drinks to a minimum. Instead try vegetables and fruit or other healthy snacks.

Weight loss can occur because you are eating less. This may be because of a poor appetite, feeling sick, having altered taste and smell, or if exhaustion makes it difficult to buy, prepare

or chew food. It will help to eat regularly, having small, softer texture, meals, quick and easy to prepare, and nourishing snacks and drinks.

If you are feeling sick, try snacking on dry, starchy foods, (such as toast/plain biscuits), eat little and often, and sip drinks throughout the day. Having something at breakfast may help.

Gut symptoms.

IBS-type symptoms, such as wind/bloating, abdominal pain, diarrhoea and constipation are common in CFS/ME. For managing IBS-type symptoms refer to the BDA Food facts on IBS.

If you need further help, ask your doctor to refer you to a dietitian. They may suggest you trial a complex and challenging diet, which reduces short-chain fermentable carbohydrates, (also known as a low FODMAP diet). It is strongly recommended that this is done with the support of a dietitian.

What about gut bacteria (microbiome) and CFS?

There is a lot of research into the role of the gut microbiome and the gut lining, or membrane "leaky gut" in CFS. So far, the results are inconclusive, and it is too early to recommend a specific diet such as gluten-free. There is evidence that some probiotics can be useful for IBS.

Myths about CFS/ME and food

There is a lot of conflicting advice and information on the internet. Many people with CFS do report an improvement in symptoms after changing what they eat. Yet there is no scientific evidence to support the claims that such as the Anti-Candida (low sugar/yeast) diet, or other restrictive diets, like the Paleo/Stone-Age or Blood Type diets, or eating chocolate help CFS.

These are not recommended and can create much more work and effort for sufferers and their carers. Although it is often thought to be better to avoid certain food types it can limit your choices, cost more and be less healthy. Many gluten-free foods, for example, are higher in fat and sugar. Many non-dairy milks are also lower in protein.

Food allergies and intolerances

CFS may affect or be affected by the immune system, but exactly how is unknown. However,

CFS food related problems are more likely to be food intolerances, (not involving the immune system), than food allergies (immune system reaction). A detailed history by an experienced healthcare professional is required to diagnose and manage these. There are many commercially available tests claiming to diagnose food intolerance and allergy. These should be avoided as they have no scientific basis.

Are Supplements helpful?

There are many claims that nutritional supplements help CFS, including multi vitamins, B vitamins, magnesium, essential fatty acids (omega-3s), carnitine, and co-enzyme Q10. Any benefit of supplements in CFS is unproven and there is need for further research in this area. Some are very expensive and contain huge doses of the active ingredient. Large doses, for instance of Vitamin A and B6, can be harmful. If you are concerned about your nutritional intake, a multivitamin and mineral supplement, that provides no more than 100% of the recommended daily amount, (RDA - see the ingredients label), may be recommended. If you are housebound, or don't go outside much, your doctor should check your vitamin D levels, as you are at risk of low Vitamin D status. A Vitamin D supplement of 10 Micrograms daily is recommended all year round for those at risk.

Summary

CFS is a medically unexplained illness, with many unproven claims of diet and supplement treatments. If making changes yourself to your diet, care needs to be taken that your diet remains healthy, nutritionally adequate, and that there is no unwanted weight loss/gain. If you need further help with your diet ask your doctor to refer to a registered dietitian.

Further information:

Food facts sheets on other topics include Healthy Eating, Glycaemic Index (GI), Supplements, Food Allergy and Intolerance, Food Allergy and Intolerance Testing and IBS as well as a copy of the Eatwell Guide can be downloaded from www.bda.uk.com/foodfacts



This Food Factsheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian. If you need to see a dietitian, visit your GP for a referral or: www.freelancedietitians.org for a private dietitian. To check your dietitian is registered check www.hpc-uk.org This Food Fact Sheet and others are available to download free of charge at www.bda.uk.com/foodfacts Written by Sue Luscombe, Dietitian and Dr Michelle Dobrota-Gibbs, Dietitian. The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts © BDA May 2018. Review date May 2021.



Dealing with Flare-Ups

Recovery from ME/CFS is a slow process and flare ups are a normal occurrence. This can leave you feeling discouraged or thinking that nothing is improving. At these times it can be natural to slip back into habitual behaviours and thinking patterns. Being aware and accepting that flare-ups are expected and normal means you have an opportunity to consider strategies to help you recognise, respond and take actions that will be helpful to get through flare-ups.

There may be times when flare-ups are more likely to occur.

- Mental or physical exertion
- Illness or infection
- Emotional stress
- Low mood
- Environmental changes
- Reverting to default patterns of thinking and behaviour that tend to increase symptoms
- Major life events e.g. marriage, bereavement, redundancy, moving house.
- No reason at all!

Flare up tips from people living with ME/CFS

“Don’t panic. Remember flare-ups are a temporary increase in symptoms, you will get through it and there are things you can do to help.”

“As best you can try to relax, plan and do things that help you relax. Restrict exposure where possible to activities and situations that increase stress levels.”

“Unhelpful thoughts are more likely to crop up in a flare up. Acknowledge them but stick to your plan move towards your values.”

“Try not to blame yourself, remember flare ups are normal in ME/CFS, it is NOT a sign of failure, damage or disease progression, focus on what you CAN do today to help.”

“Be kind to yourself.”

“Have a flare up plan, as your cognitive ability to develop and implement coping strategies may be affected. Also consider sharing your flare up plan with family and friends.”

“It is sensible to reduce activity levels in the short term and plan more frequent short rests, but try to avoid complete bed rest.”

“Afterwards reflect on what, if anything contributed to the flare up, what helped, what was not helpful, would you do anything differently or did you manage the challenge well enough.”

“Review the manual.”

Maintaining strategies

Living well with ME/CFS requires on-going commitment to minimise your suffering and live your life in line with your values. Hopefully the strategies and approaches explored on this programme will support you in doing this. This is not a quick fix or a cure for ME/CFS, it is a long-term approach, it is not easy and requires flexibility and courage, there will be set backs along the way.

Often on completing the programme participants report it is difficult to continue to prioritise their needs, but it is ESSENTIAL for our health and wellbeing. Remember self-care is about giving the world the best of you rather than what is left of you!

Maintaining coping strategies depends on being aware of when they slip, so it may be wise to plan to check in with your self-care strategies on a regular basis, perhaps weekly initially.

As mindfulness practice helps maintain awareness now is the time to decide what regular mindfulness practices you would like to take forward, maintaining a new practice or habit can be difficult here are some things that might help:

- Regularly remind yourself of the positive reasons to sustain mindfulness practice. Think about the things that are important in your life, the things you value and how mindfulness practice can help with this.
- Set realistic goals for practice
- Be kind to yourself at times when you are unable to practice.
- Ask family and friends for support in encouraging you to practice, particularly at times of stress.
- It may help to set aside a time and place to practice. Setting a reminder can help.

Whilst daily mindful practice is helpful it is equally important to consider how you approach the rest of the day. Trying to bring a kind awareness into daily life and activities as this will support use of coping strategies.

Session 6 Home practice suggestions

Daily mindfulness practice

Consider any sleep strategies you may wish to try.

Consider any diet related changes you may wish to explore.

Complete Flare-Up Plan on front cover.

Plan when you will next check in with your self-management strategies.

Plan an action you will take in line with your values this week.

Programme Review

What was the value or goal that I set at the beginning of the programme, have I made any progress towards it?

What have been the benefits of attending the programme?

What behavioural strategies have I trialled whilst on the programme?

What are my plans for the future?

ME/CFS Programme – Online Resources

Below are hyperlinks that may provide additional insights. If you click on the link the YouTube video will appear. We suggest that you watch the clips following the session. This will hopefully further support you to engage with the approach.

1: Introduction to ME/CFS and treatment approach.

Dr Charles Shepherd, medical advisor to the ME Association, and who has ME/CFS, describes the symptoms, diagnosis and treatment for ME/CFS.

[Chronic fatigue syndrome \(CFS\) | NHS - YouTube](#)

This clip explores symptoms of ME/CFS [What are Chronic Fatigue Syndrome Symptoms? - YouTube](#)

This provides more information on the dysregulation model of ME/CFS. [BACME-An-Introduction-to-Dysregulation-in-MECFS-1.pdf](#)

Clips to watch on identifying values:

'Finding your why' by Michael Junior. <https://youtu.be/1ytFB8TrkTo?t=1>

Goals 'Vs' Values by Russ Harris <https://www.youtube.com/watch?v=T-IRbuy4XtAandlist>

Introduction to mindfulness practice:

[Introduction- Getting started - YouTube](#)

Mindfulness Practice: Awareness of the Breath.

[Awareness of the breath - YouTube](#)

2: Activity management and quality rest

Pacing, activity management

[Pacing A5 booklet Oct 2023 aw.indd \(actionforme.org.uk\)](#)

Mindfulness Practice: 3 step breathing Space.

[3 step breathing space - YouTube](#)

Relaxation Practices: Tense and Relax

[10 Tensing and Relaxing - YouTube](#)

3: Physical Activity and Understanding Pain

NHS Worcestershire Adapted Tai Chi video part 1

<https://www.youtube.com/watch?v=ZbGvYXB08uk>

The following clips are designed to improve understanding of pain.

Understanding pain (5mins) <https://youtu.be/OYOi1AD5mOk>

Pain and its causes (5mins) <https://www.tamethebeast.org/#tame-the-beast>

Why things hurt (14mins) <https://www.youtube.com/watch?v=gwd-wLdIHjs>

Mindfulness Practice: Body Scan [Body scan - YouTube](#)

4: Cognitive Activity and Emotional Stress

Mindfulness Practice: Soothing rhythm breathing,

[Soothing rhythm breathing - YouTube](#)

Other examples on YouTube:

www.youtube.com/watch?v=4Z07FaTSuWM Will Devlin

[Take a deep breath - YouTube](#) Calm

5: Working with Thoughts and Communication

The following clip asks what are thoughts, where do they come from?

<https://youtu.be/7qqrZr6tPHQ>

This offers another way of relating to thoughts like trains passing through the station

<https://youtu.be/F0SWMICwtm0>

Mindfulness Practice: Leaves on a stream.

[Working with thoughts - YouTube](#)

This clip looks at working with thoughts: Passengers on the Bus by Dr Jess McCloskey

[Passengers on the Bus - YouTube](#)

6: Sleep, Nutrition and Flare-up management.

Tips for getting a good nights sleep summarised here (4mins)

<https://youtu.be/Fpoa8siZYk0>

Tips for diet, nutrition and ME/CFS.

[Chronic Fatigue Syndrome and diet \(bda.uk.com\)](#)

[ME NUTRITION CLUB | Cinnamon Days](#)

Flare up management. Tips:

[Minimizing Relapses | ME/CFS and Fibromyalgia Self-Help](#)

Useful Resources

Books

'Overcoming Chronic Fatigue Syndrome: A self help guide using Cognitive Behavioural Techniques', Mary Burgess and Trudie Chalder.

'CFS unravelled', Dan Neuffer

'The Happiness Trap', Russ Harris.

'Living Well with Pain and Illness: The mindful way to free yourself', Vidyamala Burch.

'The Compassionate Mind', Paul Gilbert.

'University and Chronic Illness: A survival guide', Pippa Stacey.

'The Fatigue Book: chronic fatigue syndrome and long covid fatigue: practical tips for recovery', Lydia Rolley

'The Sleep Book', Guy Meadows.

'Living with the enemy, coping with the stress', Ray Owen.

Mindfulness-based Therapy for managing Fatigue', Fiona McKechnie

Apps

Relaxation / Mindfulness: Headspace, Insight timer, Calm

Sleep: Pzizz, Sleepio, Sleepstation

Activity Management: Active ME

Websites

ME/CFS

www.actionforme.org.uk

excellent information on welfare rights and employment issues.

www.meassociation.org.uk

great for information on current research.

[Overview | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)

ACT / Mindfulness

www.workingwithact.com

www.wildmind.org

www.breathworks-mindfulness.org.uk

www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/

Pain

www.livewellwithpain.co.uk

www.retrainpain.org/

www.knowpain.co.uk

www.tamethebeast.org/

ME/CFS Support Groups

Sheffield ME and Fibromyalgia Group Website: www.SheffieldMEgroup.co.uk
Email: info@sheffieldmegroup.co.uk
Telephone: 0114 253 6700

Derbyshire ME Group (MED) Website: www.me-derbyshire.org.uk
Telephone: 01332 864120

Doncaster ME Group Website: www.leger.me.uk/
Email: mike@danum.me.uk
Telephone: 01302 787353

Employment Support

Sheffield Occupational Health Service [Home - Sheffield Occupational Health Advisory Service \(sohas.co.uk\)](http://www.sohas.co.uk)

Contacting the team

ME/CFS Service South Yorkshire and North Derbyshire
Michael Carlisle Centre
75, Lyndhurst Road
Nether Edge
Sheffield
S11 9BJ

0114 226 3232