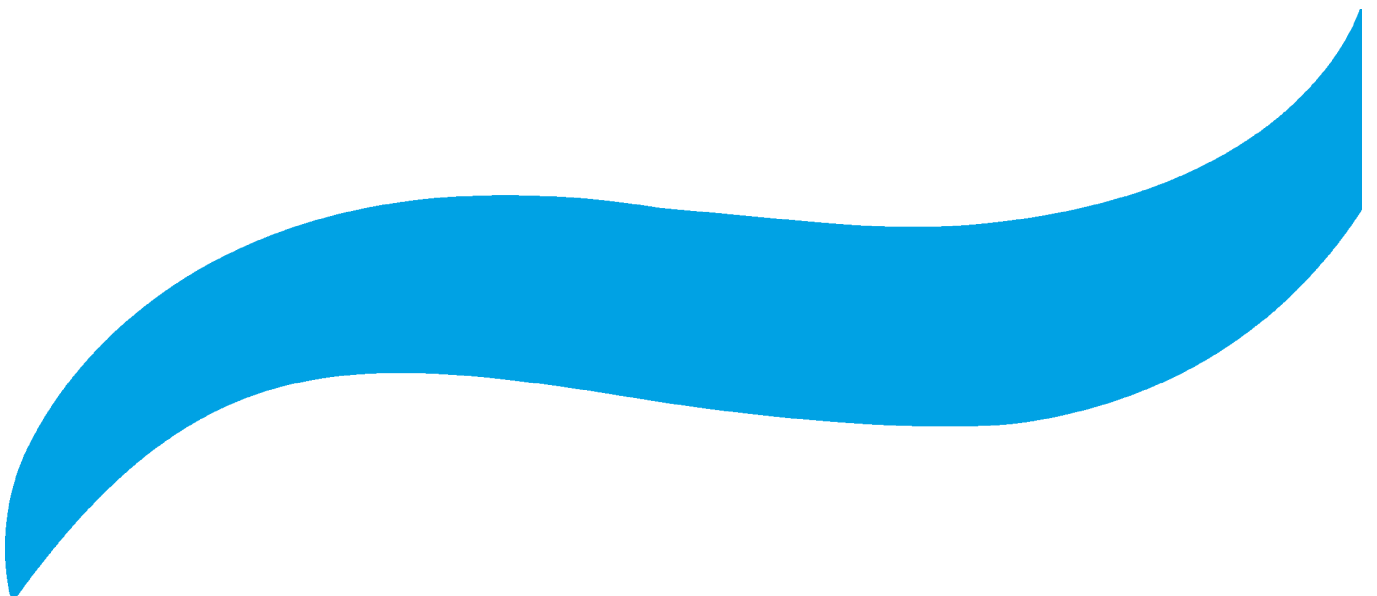




# Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

Information for patients



## ACKNOWLEDGEMENTS

### Authors

- ❖ NHS Lanarkshire

### Contributions

- ❖ NHS Lanarkshire MSK Team

## USEFUL WEBSITES

- ❖ [www.meassociation.org.uk/](http://www.meassociation.org.uk/)
- ❖ [www.sleepfoundation.org](http://www.sleepfoundation.org)
- ❖ <https://workwellfoundation.org/>
- ❖ [www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/myalgic-encephalomyelitis-me-or-chronic-fatigue-syndrome-cfs](http://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/myalgic-encephalomyelitis-me-or-chronic-fatigue-syndrome-cfs)

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## WHAT IS ME/CFS?

Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is an umbrella term for a condition where you can have many different symptoms. The most common symptom is extreme tiredness that can change from day to day and depends on many things.

[Link to information on ME/CFS on the NHS Inform site](#)

## SYMPTOMS

Below are listed some of the symptoms patients with ME/CFS experience.

Feeling extremely tired most of the time which limits your daily activities

Not feeling refreshed after sleep and rest

Taking a long time to recover after exercise / activity

Problems sleeping or getting to sleep

BRAIN FOG  
problems with thinking and focussing

Forgetting things

Muscle or joint pain

Headaches

Sore throat

Flu-like symptoms

Feeling dizzy or sick

Heart palpitations

## SEVERITY

Most CFS/ME sufferers have mild or moderate symptoms.

### Mild

- ❖ Able to take care of yourself and do light tasks around the house but with difficulty
- ❖ You can manage a full time job but have to take days off
- ❖ You have stopped all leisure activities to make sure you can stay at work
- ❖ Your days off are used to rest to let you to cope

### Moderate

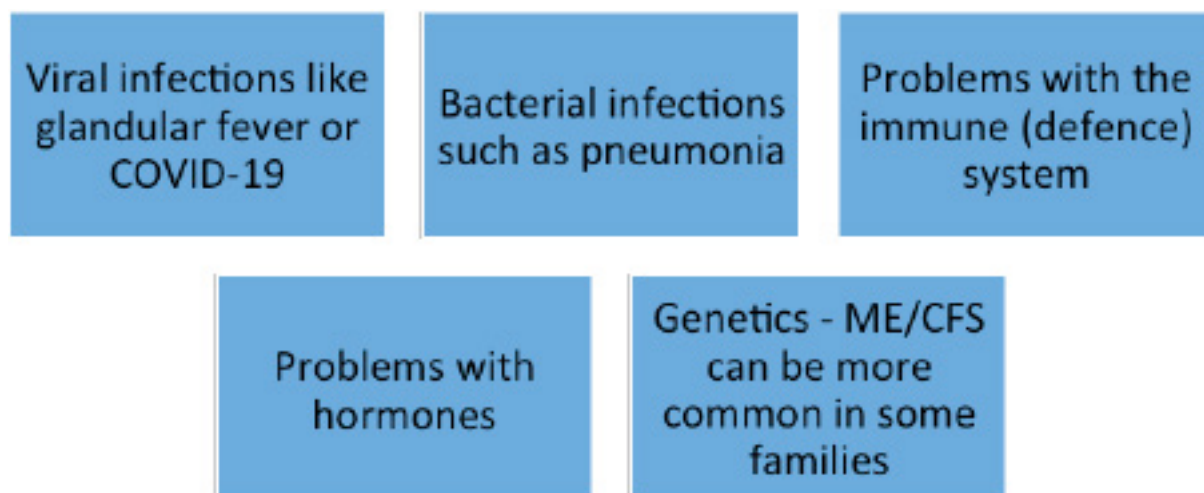
- ❖ Your mobility (walking around) is reduced
- ❖ You are not able to do all your normal daily activities
- ❖ You have 'Peaks and troughs' with your activity levels and severity of symptoms. This means that sometimes you have less symptoms so you can manage to do more. Other times your symptoms are more severe and you can't manage to do as much.
- ❖ You have stopped working
- ❖ You need rest periods during the day, and often sleep in the afternoon
- ❖ Your night time sleep is disturbed

### Severe

- ❖ You can only carry out a small amount of your daily tasks
- ❖ You have problems with mental processes such as concentrating
- ❖ You may not be able to leave the house
- ❖ Your mobility (walking around) is severely affected

## CAUSES

The exact cause for developing ME/CFS is not known. There are however some theories which could explain why people get ME/CFS. Some of these are listed below:



## DIAGNOSIS

There is no test for ME/CFS, but there are guidelines which help healthcare professionals diagnose this condition.

If ME/CFS is suspected, a GP should perform a physical examination and take a detailed medical history from you including the history of your symptoms.

To rule out any other medical condition, you may also have blood tests or scans.

It normally does take a long time to get diagnosed with ME/CFS. This is because there are so many other conditions that can give you similar symptoms.

While you are waiting for the diagnosis or if you have been diagnosed, this workbook will give you some self-management skills that could help your symptoms.

## MANAGING FATIGUE

### What is Fatigue?

It is extreme tiredness that does not go away with sleep or rest. This lack of energy can make your arms and legs feel heavy, and it can make you feel grumpy and emotional. It can reduce your concentration and motivation, so you may struggle to carry out day to day tasks.

Fatigue is one of the most common symptoms of ME/CFS and may stop you from getting back to work, cooking a meal, looking after someone, talking to a friend, or going shopping.

The amount of fatigue you have may change from day to day (or hour to hour), and certain activities may make it worse, as they can cause other symptoms (like pain). An increase in your level of fatigue can last for several hours (or days) and may be slow to improve.

### Some of the most common features of fatigue are:

- ❖ Struggling to carry out every day activities
- ❖ Whole body tiredness
- ❖ Feeling of heaviness in the body
- ❖ Weakness
- ❖ Lack of concentration
- ❖ Having no energy
- ❖ Brain fog
- ❖ Pain
- ❖ Changes in eating habits
- ❖ Feeling unable to cope
- ❖ Feeling grumpy
- ❖ Difficulty solving problems
- ❖ Finding it difficult to chat
- ❖ Struggling to make decisions
- ❖ Feeling 'off balance'
- ❖ Feeling emotional
- ❖ Not coping with noise, smell, or bright light
- ❖ Problems sleeping

### Do you have some of these symptoms?

Causes of fatigue can be physical, mental, emotional and environmental (your surroundings).

Understanding what makes you fatigued can help you take steps to make it better. In this part of the workbook we will look at how fatigue affects your life, and give you tools to help you manage it.

## Boom and Bust

If you have fatigue, you may feel that you are going round and round in circles. You may try to do as much as possible when you have some energy, and then feel much worse after because you have done too much. When you feel worse you need lots of rest to help you recover. This is called Boom and Bust.

Are you in a Boom Bust cycle? Is fatigue taking over your whole life? Let's look at how you can break this cycle to help gain control over your day to day activity.

## Fatigue and Energy Levels

We all have our own battery to give us energy during the day. When we run out of energy, we need to recharge our battery. When you are fatigued, it can take longer than 'normal' to recharge your battery. That is why it is important to keep track of our energy /battery levels.

Think about how much energy you need to carry out each daily task. You can do this by working out how you feel and what you can do when you have different energy levels. Start by filling in the following statements:



When my battery is fully charged I feel...  
.....  
.....  
.....



When my battery is half charged I feel...  
.....  
.....  
.....



When my battery is empty I feel...  
.....  
.....  
.....



When my battery is empty I can do...  
.....  
.....  
.....



It is important to sleep, rest, eat and drink enough to help recharge your batteries and allow your energy to recover. Now that you know how you feel when your battery is full, half full and empty, let's look at how you can manage your fatigue by pacing your activity.

## PACING

### Pacing your Activities

Pacing is a way of balancing your activity levels without making your fatigue worse. It involves balancing activity with rests to make sure your battery never runs out of charge. Pacing is one of the 5 Ps that can help you break out of the Boom and Bust cycle and build your energy levels.

#### The 5 Ps are:

- ❖ Prioritising the most important tasks in your day
- ❖ Planning how you will carry out these tasks
- ❖ Pacing to break daily tasks down into smaller parts
- ❖ Position yourself correctly
- ❖ Permission to say NO or ask for help

## PRIORITISE

Ask yourself the following questions to find out which of your daily activities are important for today:

- ❖ What do I NEED to do today?
- ❖ What do I WANT to do today?
- ❖ What can wait until another day?
- ❖ What can I ask someone else to do for me?

Think about which activities are most important to you each day, and make those activities your priority.

## PLAN

Planning what you need to do on a daily or a weekly basis can help you to organise your activities and build in time to recharge your batteries.

It is helpful to plan all the tasks you need to do in each room ahead of time. This cuts down the amount of walking and energy needed. Try to do all the tasks in one room before moving to the next. Take your time and have breaks when you need them.

Which times of day are best for you to be active or at rest? Do you have more energy in the morning or at night? Try not to do too much in one day. For example, food shopping, laundry, and changing the bed, can be done on different days with rest days in between.

Top tips for planning your day:

- ❖ Collect all the items you need before you start a task
- ❖ Sit to carry out a task if possible
- ❖ Take regular breaks
- ❖ Do one thing at a time – try not to multi-task
- ❖ Ask for help from friends or family where you can
- ❖ Use delivery services to bring items to you – e.g. online shopping



## **PACE**

It is important to balance activity with rest. You may need to rest during activity and allow yourself some extra time to finish what you are doing. Pacing will help you have enough energy to manage your daily activities. It will help you recover faster if you work on a task until your battery is half full rather than empty. Slow and steady wins the race!

Top tips for pacing yourself during the day:

- ❖ Break up activities into smaller tasks
- ❖ Use the phone or internet rather than going out
- ❖ Spread tasks throughout the day
- ❖ Build in regular rest periods
- ❖ Plan to rest and recharge between activities
- ❖ Set an alarm (on your phone) to remind you to stop and rest
- ❖ Sit and rest when you can

## **POSITION**

Having good postures and comfortable body positions when carrying out tasks (including resting) is really important to help you save energy. For example, sitting in a supportive armchair when watching TV or leaning your hips against the kitchen worktop when washing the dishes.

Good posture lowers the amount of energy needed, as muscles don't need to work as hard. If possible avoid stretching, over-reaching and bending down. Think about how you sit and stand during the day - can you change your posture or position to stop you getting uncomfortable?

Top tips to improve your posture during the day:

- ❖ Get closer to a task to avoid over-stretching
- ❖ Use both hands when lifting and carrying
- ❖ Keep frequently used items close together (tea and coffee near the kettle)
- ❖ Slide items along work surfaces
- ❖ Sit down to do tasks if you can (peeling potatoes over a bowl on the table, or sitting on the toilet when brushing your teeth)
- ❖ Use gravity to help you – allow something to fall rather than place it on the floor

## **PERMISSION**

Allow yourself NOT to do tasks that make you breathless and fatigued. It is OK to say NO, and also OK to ask for help from family or a friend when you are finding things tough. Show them your activity diary (see page 22) so they get an idea of what you can manage. Tell them what you need help with. Instead of thinking 'I must' or 'I should', try to change your thinking to 'I choose to', 'I would like to' or 'I wish to'. Don't force yourself to do too much, and stop and rest if you are getting too puffed out or tired.

## ENERGY CONSERVATION

How many times have you put your mobile phone onto power saving mode because you want it to last a bit longer? Your phone is saving the battery from running out of charge, and this is what you need to do too. The next part shows you how to save your own battery to cope with fatigue and tiredness by using your energy in the best way.

### Washing & grooming

- ❖ Sit to brush your teeth and dry your hair
- ❖ Avoid aerosols (spray cans) and strong scents.
- ❖ Short hair is quicker to dry and style.
- ❖ Wash hair in the shower, keep elbows low and chin tucked in.
- ❖ Support elbows on counter when grooming
- ❖ Do not hold your breath when shaving.
- ❖ Use an electric toothbrush and shaver.

### Bathing and showering

- ❖ Wash at a time when you have enough energy
- ❖ Allow plenty of time.
- ❖ Gather everything you will need, including clothes.
- ❖ Keep items within reach.
- ❖ Use a stool/chair in your shower.
- ❖ Sit to undress, wash, dry and dress.
- ❖ Use a long handled sponge to wash back and feet.
- ❖ Decrease steam by turning cold water on first and slowly adding hot water.
- ❖ If oxygen is prescribed for exercise, use it when showering.
- ❖ Open the bathroom window to allow steam to escape.
- ❖ Use a towelling bathrobe to dry your body.

### Dressing

- ❖ Before starting, gather all YOUR clothes together.
- ❖ Keep control of your breathing. Breathe out with effort.
- ❖ Sit down to get dressed.
- ❖ Dress the lower half of your body first.
- ❖ Cut down on bending by crossing one leg over the other when putting on socks and shoes
- ❖ Long handled tools can help you put on socks, pants and shoes.
- ❖ Pull up pants and trousers at the same time in one stand.
- ❖ Slip-on shoes, velcro straps or elastic laces may help.
- ❖ Dress the upper body last with buttons and zips on the front of clothes

## **Cooking**

- ❖ Cook larger amounts and freeze some.
- ❖ Prepare part of the meal ahead of time.
- ❖ Use recipes that need little time and effort.
- ❖ Gather all items before beginning.
- ❖ Sit if possible (to cut up food and wash dishes).
- ❖ Make one pot meals.
- ❖ Use pre-prepared fresh or frozen products.
- ❖ Serve food from the baking dish.
- ❖ Use electric tin openers and other powered kitchen tools

## **After meal clean up**

- ❖ Rest after your meals before starting to clean up.
- ❖ Have everyone clear their own place setting.
- ❖ Use a trolley to transport items instead of carrying.
- ❖ Your washing up bowl should be at a comfortable height.
- ❖ Wash dishes in a circular motion.
- ❖ Let dishes soak so you don't need to scrub them.
- ❖ Let dishes air dry.
- ❖ Use a dishwasher if you have one.
- ❖ Use rubbish disposal, empty bins frequently or have a family member do it

## **Shopping and meal planning**

- ❖ Order online if possible
- ❖ Organise your shopping list to match the layout of the supermarket.
- ❖ Shop when the store is quiet.
- ❖ Get help reaching for items and for carrying heavy bags.
- ❖ Ask the shop assistant to pack your shopping lightly.
- ❖ Make a few trips to bring your shopping into the house.
- ❖ Take the cold and frozen food in first, and get the other items later after a rest.

## **Housework**

- ❖ Spread out chores over the whole week.
- ❖ Clean a different room each day.
- ❖ Sit down to dust and use a long handled duster.
- ❖ Use a light weight Hoover if possible.
- ❖ Use long handled cleaning attachments on the Hoover.
- ❖ Use a mop to clean up spills instead of bending down.

**Laundry**

- ❖ Sit to iron, sort clothes and fold the laundry.
- ❖ Move wet clothes into a dryer a few items at a time.
- ❖ Get help to fold large items such as sheets.
- ❖ Buy clothes that are easy to wash and need little ironing.
- ❖ Use a trolley to take washing outside to hang it up.
- ❖ Use a low washing line to avoid reaching up.

Use this section to make any notes to help you manage your fatigue and save your energy. If you want more information on managing your fatigue, please visit the web links at the end of this section.

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## RELAXATION

When you are stressed your body will naturally become tense. Your muscles will be tight, you may clench your fists, your breathing may become faster, your blood pressure might higher. You may also have a headache, back pain and your heart may beat faster.

Relaxation techniques can help your body feel less tense can help you worry less. Relaxation techniques will help your muscles and your mind feel more relaxed. There are a number of different relaxation techniques you can try to help reduce tension and relax your mind.

### **Remember:**

- 1) You have to practise often. If you have never done relaxation before then your body and your mind will be learning new skills. It takes practice to feel confident using them.
- 2) Try to do a relaxation exercise when you feel calm, to make sure you can focus on it. The more you practise, the easier you'll find it to use relaxation techniques when feeling very stressed.

### **Below you can find different types of relaxation exercises**

Feel free to explore them and use the one's that you find the most helpful.

#### **Progressive muscle relaxation**

<https://www.youtube.com/watch?v=86HUcX8ZtAk&t=291s>

#### **Relaxed Breathing**

<https://www.youtube.com/watch?v=jPMw2PlqJC8&t=11s>

#### **Guided imagery**

[https://www.youtube.com/watch?v=t1rRo6cgM\\_E](https://www.youtube.com/watch?v=t1rRo6cgM_E)

#### **Safe place**

<https://www.youtube.com/watch?v=G1bxxiiXc48>

## **How to comfort yourself**

There are things we all do to help us feel calm and relaxed when we're feeling emotional. These activities usually involve our senses, and they can be quick and helpful ways to feel calmer and more in control of our emotions.

Think about what you do when you are feeling stressed. Do you have a shower? Cuddle under a blanket? Have a cup of tea? Below you can find examples of such activities.

### **Visual**

- ❖ Looking at photographs of happy memories
- ❖ Looking at pictures of relaxing/fun places
- ❖ Looking at the nature around us
- ❖ Looking at art
- ❖ Watch your favourite TV show/Movie

### **Hearing**

- ❖ Listening to music
- ❖ Listening to the sound of nature (waves, birds etc)
- ❖ Listening to an audio-book or a guided imagery exercise
- ❖ Listen your favourite TV show/Movie

### **Smell**

- ❖ Smell scented candles
- ❖ Favourite perfume, body mist, body cream
- ❖ Cook a meal that smells delicious
- ❖ Go to a place where you might enjoy the smell (park, flower shop, perfume shop, bakery, restaurant)

### **Taste**

- ❖ Cook or buy your favourite meal and eat it slowly
- ❖ Make a cup of coffee/tea/smoothie
- ❖ Chewing gum with your favourite flavour
- ❖ Eat some fruit

### **Touch**

- ❖ Cuddle your pet
- ❖ Hug someone who you care about
- ❖ Cuddle under a blanket
- ❖ Touch/wear any fabric that seems soothing to you (something smooth, velvety, fluffy etc)
- ❖ Hot/cold showers
- ❖ Hot water bottle

Think about what you find relaxing and try to do those activities when feeling stressed. It can be helpful to use techniques that have either worked before or that made you feel safe and relaxed before. Feel free to ask friends and family for their own ideas but remember that what works for one person does not work for others.

## RELAXED, TUMMY BREATHING

This will help you relax, slow down your breathing, loosen off muscles and rest.

Breathing well (i.e. slowly, through your nose to make your tummy rise), uses up less energy and will help you recover some energy.

### Guide to tummy breathing

1. Lie on your back (on a sofa or your bed) with a pillow under your head and knees.
2. Close your mouth and try to breathe through your nose.
3. Let your face relax.
4. Keep your tongue still and sitting behind your top teeth.
5. Place one hand on your tummy and one hand on your chest.
6. Let your shoulders, chest and arms drop until they feel heavy.
7. Relax your legs until they feel heavy
8. Aim to practise this for 20 minutes every day.



As you relax, you should notice that your tummy begins to rise as you breathe in and falls as you breathe out. This is tummy breathing. If you do not feel this, let your shoulders, arms, chest and legs relax until they become heavy.

To help you feel your tummy breathing you may find it useful to place a small weight over your upper tummy, such as a wheat bag, hot water bottle or a book.

As you get used to tummy breathing, you will notice a short pause between breathing out and breathing in. This is normal. Once you feel comfortable with tummy breathing lying down, try it when you are sitting and standing.



Tummy breathing should feel relaxed and easy. This is how your body wants to breathe. The more you practise tummy breathing, the easier it will become.

## MINDFULNESS

ME/CFS symptoms can affect our lives in ways we find very upsetting. We might have lots of worrying thoughts. This can often be about the past or things in the future. These thoughts can grab our attention and stop us from doing things we enjoy. This habit of worrying can sometimes make us feel low in mood.

It is helpful to know when we have lots of worrying thoughts and strong feelings. If we are aware of this, we can switch our attention to activities that either make us feel good about ourselves or that are meaningful. Taking time in our day to pay attention to our thoughts, feelings and surroundings in the moment is called mindfulness.

### Mindfulness is a good thing to try practise. Let's try some:

1. Sit or lie in a comfortable position.
2. Notice the touch of your body on the seat, how does each part feel?
3. Pay attention and notice your breath – don't worry about HOW you're breathing right now, just FEEL it. Where do you feel the air moving when you breathe?
4. Notice how you feel. Are there any emotions coming up? Are there any thoughts coming up?
5. Notice how they feel but try not to do more than that; just notice it.

This is a simple routine of mindfulness – just noticing how things are feeling – being mindful of them.

It is important to notice all emotions and feelings. Not just the happy or sad ones but everything in between. Remember, when practising mindfulness, you don't have to do anything with your feelings or emotions that come up – you just notice them and then let them go.

### Below is a link for a mindfulness activity:

#### **Meditation for Beginners featuring Dan Harris and Sharon Salzberg**

<https://www.youtube.com/watch?v=C-sFh5CWsQo>

The mind can be such a confusing and tricky thing! To help explain your emotions and why it can be important to slow down and pay attention to what is going on, here is a video on the evolution of the mind:

#### **The Happiness Trap: Evolution of the Human Mind by Dr. Russ Harris**

<https://www.youtube.com/watch?v=kv6HkipQcfA>



## VALUE BASED LIVING

Managing your ME/CFS symptoms can take over your life. We might become too focused on finding a way to deal with our symptoms so we can continue on with our lives and normal activities. These feelings are normal as it is a big part of our lives. Unfortunately, it can mean that we may lose track of what is important to us.

Doing the things that matter to you can help improve your mood and help you to continue to live a rewarding life. To do this, we must know what our values are.

Values are statements about how we want to behave and what we want to be doing with our lives. We can use these values to help guide us through life when we need to make decisions and plan activities.

It is helpful to focus on our values rather than our goals because it gives us more choice, freedom and flexibility in how we go about our day. This is important if our ME/CFS symptoms are making us very upset or are stopping us from doing the things we enjoy.

### Let's look at the example of 'Anne':

"Before having ME/CFS I used to enjoy walking every week with my friend. This helped both my physical and mental health. Now I can't do this I feel very down, as it is just too tiring for me."

### Try to think about or write down what values are behind why Anne loves walking with her friend:

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Examples of what values could be part of this activity are: connection, adventure, communication, friendship.

### Now with a values approach let's see what Anne does now:

"It was not until I thought about it, being out in the open air somewhere new and having that connection with my friend was what mattered to me. We now meet somewhere for a picnic, snack or coffee; we've gone to so many new spots and still enjoy the time together like before.

Another helpful way to start identifying your values is by reflecting on times when you felt really good about yourself and really confident that you were making good choices. You could ask yourself the following questions:

- 1) When was I the happiest?
  - ❖ What was I doing during this time?
  - ❖ Who was I with?
  - ❖ Where was I?

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2) When was a time that I felt proud?

- ❖ Why was I proud?
- ❖ Did anyone else share my pride?
- ❖ What other factors contributed to me feeling proud?

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3) When was a time that you felt most fulfilled and satisfied?

- ❖ What need or desire was fulfilled?
- ❖ How and why did the experience give your life meaning?
- ❖ What other factors contributed to your feelings of fulfillment?

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4) Why is each experience important and memorable?

- ❖ What do you think some of the values are underpinning these experiences?

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**FOCUS ON  
VALUES**  
rather than goals

Once values have been identified, think about how you can try to do activities with these and your symptoms in mind.

You will also find below a link to videos relating to values and taking life into a meaningful direction.

**The Choice Point: A Map for a Meaningful Life by Dr. Russ Harris**

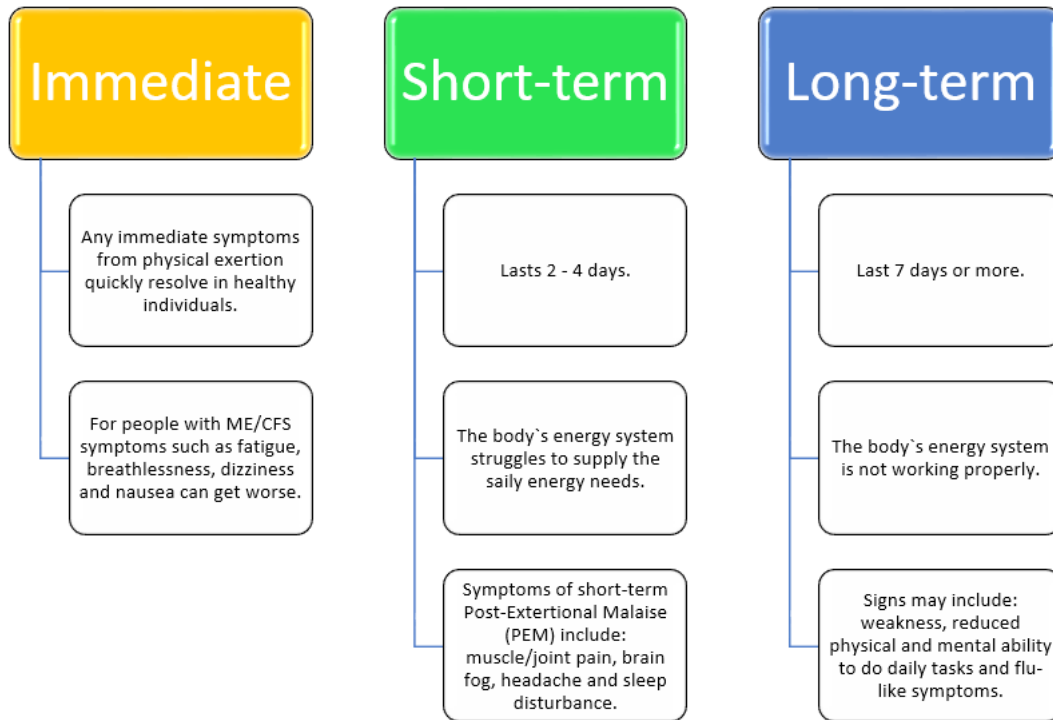
<https://www.youtube.com/watch?v=OV15x8LvwAQ>

**Values vs Goals by Dr. Russ Harris**

<https://www.youtube.com/watch?v=T-IRbuy4XtA>

## EXERCISE WITH ME/CFS AND POST EXERTIONAL MALAISE (PEM)

- ❖ It is common for your symptoms to get worse after you do something that uses energy. This is called Post Exertional Malaise (PEM).
- ❖ PEM is something that tends to happen with ME/CFS.
- ❖ PEM is when your symptoms get worse after physical, cognitive (thinking) or emotional effort.



### The following 2 questions may help us to find out whether you experience PEM.

1. Do you experience severe fatigue (extreme tiredness) with at least 3 symptoms in the categories below?
  - a) Feel unwell
  - b) Feel weak
  - c) Don't sleep well
  - d) have pain
2. Does it take a day or more to recover if you have had to use a lot of energy?

If the answer to both questions is yes, then you may have PEM and so should avoid the activity that makes your symptoms worse.

When people with fatigue do too much, or use up all their available energy supplies, they stop being able to carry out activities. This is not improved with a long rest or a good sleep. For some people, this means that they are unable to work or carry out household tasks without making their symptoms worse.

In some severe cases, the things that our bodies normally do such as: digestion, heartbeat and breathing, can make symptoms worse. People with fatigue and PEM have changes in the way their energy is made. The normal way that we produce energy through using oxygen is reduced (aerobic fitness), and the body tries to produce energy in another way instead (this is called anaerobic). Anaerobic energy production tires you out more quickly. It takes much longer for your energy levels to recover if you have fatigue, so your symptoms might last longer.

## **How to I deal with it if it happens?**

### **Finding your comfort zone based on how you feel.**

Your baseline is what your 'normal' is – this is not your pre ME/CFS normal. It is when your body has no symptoms and feels 'normal'. There are things that you can do to help you find your baseline.

### **Build in rest periods.**

The level of activity/ rest that you can manage without making your symptoms worse is known as your baseline activity. Finding your baseline can take time. Building in enough rest around your activity will gradually allow you to do a little bit more, especially if you use the ideas in the pacing section.

### **Self-monitoring activity**

The Workwell Foundation advises that if you have PEM, you should have a maximum heart rate of 15 beats per minute above your normal resting heart rate, when you are doing any activity. This means that if your heart rate climbs to 15 beats higher than your resting heart rate, you should stop the activity to prevent PEM. A heart rate monitor may help you to keep an eye on this at home. This is because above this rate your body naturally starts to use the method of creating energy without oxygen. This means that your energy will run out faster.

### **How to calculate your resting heart rate?**

- ❖ Rest for 10 minutes
- ❖ Feel your pulse at the thumb side your wrist with 2 fingers
- ❖ Count the number of beats for 30 seconds
- ❖ Multiply this by 2 to get the number of beats per minute

### **Pedometers/Step Counters**

Using a smart watch or phone, to count your steps can help you see how active you have been. This is very helpful if physical activity is a trigger for your PEM. It may also help you to find out how much of an activity you can do without making your symptoms worse. This can help you with pacing.

### **Resting**

Resting your body, mind and senses will allow you to recovery quicker. Resting will differ between people, depending what triggers their PEM. This may involve lying in a quiet dimly lit room; it could be guided relaxation, mindfulness, or breathing work.

### Key points:

- ❖ Some people might find watching television or listening to music restful, but if you have sensory triggers, these activities will make your symptoms worse.
- ❖ It can be difficult to rest if you feel bored, if there is pressure on you to get back to doing your 'normal' activities, if you want to use the energy which you have gained after resting, or if you want to distract yourself from the symptoms you are having when you are resting.
- ❖ Rest takes practise and willpower.
- ❖ Some patients may have a combination of reduced exercise tolerance, be weaker, and have PEM. Patients with PEM must deal with this first before thinking about dealing with the other two.
- ❖ By keeping a close eye on how your body copes with an activity, you can use your symptoms to help you manage things.
- ❖ If you have reduced exercise tolerance, or if you are weaker, but you do not have PEM, it is safe for you to gradually increase the amount of activity you are doing. You will not make yourself extremely tired or have the problem of your symptoms getting worse.

**'No pain, no gain' does NOT apply here and can be damaging to your recovery.**

## ACTIVITY DIARY

Please look for a sample activity diary on the next page, which will help you to keep an eye on your fatigue throughout the day. An activity diary helps you record what activities you have carried out over the space of a week and the fatigue you felt after. Activities may need physical, mental, emotional, sensory or social effort. This diary will help you see what activities are bringing on (or triggering) your symptoms. If you are able to find triggers and cut them out, or reduce them, this should help with your symptoms and energy levels. As will building in rest periods.

### How to use an activity diary

- ❖ Look back at page 7 to see how you feel and what you can do when your batteries are fully charged, half full and nearly empty
- ❖ Think about what activities you NEED to do and what you WANT to do
- ❖ Prioritise, Plan and Pace your day
- ❖ Make sure you have good posture during tasks
- ❖ Allow yourself to say NO to tasks
- ❖ Spread rest and activity evenly throughout your day
- ❖ Include activities that you enjoy and are fun to do
- ❖ Break activities down into chunks
- ❖ Try to do fewer physical activities in the evening
- ❖ Use the scale below to score how you felt after each period



Day	6-9pm		9-12am		12-3pm		3-4pm		6pm - bedtime	
	Activity	Score	Activity	Score	Activity	Score	Activity	Score	Activity	Score
Mon										
Tues										
Wed										
Thurs										
Fri										
Sat										
Sun										

## What is exercise tolerance?

Exercise tolerance is how much you can exercise before you have to stop. This will also tell you how you will manage to do your daily activities. The things that will make you stop are: feeling breathless, fatigue (extreme tiredness) and/or pain. We want you to stop before you are feeling breathless or fatigued.

Poor exercise tolerance will happen if you have not been moving about for a long time or if you become unwell. This means that you are not able to do as much as you used to be able to.

Problems with your heart, lungs, nerves, bones or muscles can stop you from being able to exercise. This can make you feel breathless when you are walking, or going up and down stairs. You may also feel weaker than you did before, and tired during and after activity if you had ME/CFS.

Safe rehabilitation can make you fitter and stronger.

### Start low and go slow.

This chart on your right shows the BORG scale which helps to measure how hard you exercise.

You should aim to be between 11 and 13 when exercising.

You must start at a safe level for you.

Some people will find that marching on the spot for 1 minute may be enough to start with.

**You should only think about increasing how hard you exercise if you have no new symptoms, or if your symptoms are not worse 24-48 hours after you have exercised.**

Everyone is different in how much exercise they can do. You have to try and test what works for you and what does not make you feel more unwell.

It is important that you do what is good and safe for you and if you don't know, speak to a person who works in healthcare who can help you. This will make you fitter safely.

6	No exertion	
7		
8	Very light	
9		
10		Breathing a bit deeper, but still comfortable
11	Light	
12		Breathing harder, but still able to hold a conversation
13	Somewhat hard	
14		
15	Hard	Starting to breathe hard and uncomfortable
16		
17	Very Hard	
18		
19		Extremely hard
20	Maximal exertion	

## What is deconditioning?

Losing muscle will make you weaker. It is harder to do your daily activities like housework, preparing meals and exercise. This means you are deconditioned. If you are deconditioned, you will have to work harder when you are doing activities, you may tire more quickly, and you may be more breathless.

## What causes deconditioning?

- ❖ Long stay in a hospital
- ❖ Having long-term problems like ME/CFS
- ❖ Injuries like broken bones or back pain
- ❖ Bad eating habits
- ❖ Obesity
- ❖ Age

## Examples of strengthening exercises

Once you are managing everyday activities, you may feel ready to start exercising. Increase your activity and exercise levels gradually. If you get tired, stop and rest, then start again once you feel better.

**No exercise should be painful. If you experience pain, chest pain, or feel faint or dizzy during exercise, you should stop immediately and not restart your exercise programme until you have been seen by a health care professional.**

## How often should I do the exercises?

- ❖ Short, regular bouts of exercise may be easier for you.
- ❖ Repeat each exercise five times
- ❖ If this is too difficult, do three.
- ❖ If it is too easy add two or more
- ❖ If any exercise causes you a problem, STOP.



## SLEEP

### Some Sleep facts:

- ❖ An average adult sleeps for about 7 – 8 hours per night.
- ❖ Some people need more sleep than others to feel awake in the morning.
- ❖ It is not about how much you sleep but how well you sleep.

### What happens when we fall asleep:

- ❖ During sleep, a person goes between Rapid Eye Movement (REM) and non-REM sleep cycles.
- ❖ Non-REM sleep is made up of light and deep sleep.
- ❖ Light sleep is the first stage of sleep where your eyes and muscles are not very active, and your body is being prepared for deep sleep.
- ❖ As you go into deep sleep your brain and muscles stop being active, your blood pressure decreases and your heart and breathing slow down.
- ❖ If you are woken from a deep sleep you may be confused and difficult to waken.
- ❖ REM sleep is the last stage of sleep where your brain is very busy and your eyes move quickly.
- ❖ REM sleep is where you dream and your muscles are still
- ❖ There are usually spells of 3-5 REM every night. This is when we deal with our emotions and stress and also remember memories.
- ❖ The idea is that during one night of sleep we have a good mixture of these different stages of sleep. This will help us feel awake in the morning.
- ❖ Sometimes when we are stressed and worry too much for too long, our brain does not slow down and we do not get the `deep` sleep stage. This means we don't recharge our batteries fully and we wake up tired.

**Table below**

**offers some advice which you can incorporate in your night time routine to help with your sleep**

DO	DON'T
Have a warm milky drink before bed (milk, Ovaltine, Horlicks)	Avoid too many drinks with caffeine in them (e.g. coffee, tea, cola). Avoid them at all 6-8 hours before bed
Have a lavender or camomile tea before bed	Avoid drinking alcohol – it may help you to fall asleep but it disrupts the sleep itself, wakes you up often and causes you to not feel rested after sleeping
Eat a light meal earlier	Avoid heavy, rich and spicy evening meals Avoid having cheese as it's known to give you nightmares
Reduce the amount of noise and light that comes into the bedroom as much as you can	Avoid smoking just before going to bed
Have a long, hot bath before going to bed - Lavender bath products or scented candles are especially good as they can help you relax	Avoid exercising up to 2 hours before bedtime
Relax by: meditation, reading a book, imagery exercises (see the relaxation section of this workbook), muscle relaxation etc.	Avoid staying up late chatting with friends either in person, online or on the phone
Listen to some relaxing music or radio Possible relaxing radio stations include: Classic FM (99.9-101.9 FM) – classical music Radio 4 (92-95 FM) – relaxing chat Magic (105.4 FM) – relaxing contemporary music	Avoid using a computer or watching TV before going to bed
Make sure that your room is cool but not cold (around 15°C)	Avoid having the heat up too high in your room
Only go to bed when you are really tired and your eyes feel heavy	Avoid staying in bed awake for longer than 15 minutes (If you're lying in bed awake, get up, briefly do something (eg, go to the bathroom) then go back to bed and try again)
Remove your clock from the room or turn it away	Avoid checking the time during the night as it may make you feel more anxious and keep you awake.
Use your bed for sleeping	Avoid spending the day in bed and using it as a place for other activities like watching daytime TV
Try to stay awake during the day - Being outdoors for 30 mins has been shown to give you a better quality of sleep - Going for a short walk during the day when you are very sleepy will help you to feel more awake	Avoid napping during the day

## Improving Sleep: Goal Setting Sheet

Some people find planning to try one or two of the sleep techniques at a time helpful. You may wish to use the example planner below to help you try and stick to your plan. You can record how helpful you found each technique, or create your own plan. Don't forget, there is more than one reason why people have a bad nights sleep, so don't give up on a sleep technique without giving it a number of go's!

Week to try new technique	Technique	Plan (to be completed by you)	Rating (out of 5)*
..... /..... /.....	Avoid caffeine/smoking 6-8 hours before bedtime	I will not have caffeine/a cigarette after ..... pm	
..... /..... /.....	Limit alcohol use	I will have no more than ..... drinks this evening	
..... /..... /.....	Exercise regularly but not within 2 hours of bedtime	I will ..... for ..... minutes at ..... : ..... (time) on the following days: .....	
..... /..... /.....	Make sure your bedroom is a comfortable temperature, quiet and dark with a good mattress and pillow.	I will make the following changes to my bedroom: ..... ..... ..... .....	
..... /..... /.....	Take a hot bath 1-2 hours before bedtime	I will take a hot bath at ..... pm	
..... /..... /.....	Have a warm milky drink and a biscuit/light snack before bed	I will drink a mug of ..... and not ..... or ..... before bed	
..... /..... /.....	Avoid naps during the day	I will try not to nap. If I must I will limit it to ..... minutes about 8 hours after I awake and will use an alarm to wake me	
..... /..... /.....	Avoid clock watching	I will remove the clock from my room. If I need it for an alarm I will turn the clock to face the wall or put it out of sight and reach	
..... /..... /.....	Stay on a regular sleep routine	I will get up at ..... am 7 days a week no matter how poorly I slept that night	

\*(1 = made it worse, 3 = no change, 5 = big difference)

You may also find the sleep diary below useful to track your sleep and see how good it has been.

## DAILY SLEEP

Complete the diary each morning (Day 1 will be your first morning).

Don't worry too much about giving exact answers, an estimate will do.

Questions	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	Day 8
1 At what time did you go to bed last night?								
2 After settling down how long did it take you to fall asleep?								
3 After falling asleep, about how many times did you wake up during the night?								
4 After falling asleep how long were you awake during the night in total?								
5 At what time did you finally wake up?								
6 At what time did you get up?								
7 How long did you spend in bed last night (from first getting to finally getting up)?								
8 How would you rate the quality of your sleep last night?								
1      2      3      4      5								
V.Poor                  V.Good								



## SETTING GOALS

After going through this workbook we think it is important that you know how to keep an eye on how you are doing, and how to make sure you know exactly what you are aiming for.

In healthcare we always aim to set SMART goals, both with people we work with, and for ourselves.

### What is a SMART goal?

<b>Specific</b>	You're more likely to reach your goals if they are specific. For example - "I want to be able to exercise" isn't very clear but "I want to be able to get back to riding a bike" is easier to work towards.
<b>Measurable</b>	It is easier to know when you have reached a goal if it can be measured. Distance, a time limit or the number of times you do it are ways to measure goals; e.g. "I want to be able to cycle 5 km with ease".
<b>Achievable</b>	It is important to be honest with yourself and realistic. If you have never cycled in your life and you don't have a bike, maybe this goal will be too hard, and you are setting yourself up for a fail.
<b>Rewarding</b>	Every time you set yourself a goal and you reach it you have a certain feeling. It might be happiness, maybe relief or maybe sense of pride and progress. Make sure that the goals you set yourself give you that positive feeling and they mean something to you.
<b>Timed</b>	Set yourself a time to achieve your goal. Treat it more like a check date for the goal. You may change the time it will take to get there but at least you know how much time you have given yourself to check how close you are to reaching your goal.

So to sum up, if we take an example of cycling how would the SMART goal look like?

Have a go to set yourself a SMART goal first and compare it to this:

In one month, I will be able to cycle 5km without stopping.

- ❖ Choose to set yourself goals about activities that mean something to you. They don't always have to be exercise or physical activity. It may be that what matters to you is actually being able to go out for dinner with your family or friends, or perhaps even doing some gardening. Either way, make sure that your goals are important to you.
- ❖ Make sure that you set yourself small steps and small actions to reach your goals. That way you can keep an eye on how you are getting on. However, if things change, you don't feel guilty about changing the time you are giving yourself, or even changing your goals.
- ❖ Keep track of your goals to remind yourself of what you are trying to reach. You might want to use the form below to help you do this.

SHORT TERM GOAL (days)	THINGS I CAN DO TO ACHIEVE IT	DATE SET	DATE COMPLETED

LONG TERM GOAL (weeks/months)	THINGS I CAN DO TO ACHIEVE IT	DATE SET	DATE COMPLETED

## SUMMARY

How you recover from Chronic Fatigue Syndrome depends on how severe your symptoms are. This workbook gives you some information on ways to treat some of the symptoms of your condition.

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