



Introductory Handbook for ME/CFS and Post-COVID Fatigue

This handbook is produced by the RDUH ME/CFS Service to provide information and guidance for patients with ME/CFS and Post-COVID fatigue.

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

ME/CFS is recognised as a long-term neurological condition by the World Health Organisation (WHO, ICD-11. 2023). It is recognised as a **fluctuating condition**, and people may have symptoms for many years before being diagnosed.

“ME/CFS is a condition defined by symptoms which are caused by dysregulation in multiple systems in the body including the immune system, the autonomic nervous system, the endocrine system and the metabolic systems” (BACME, 2022).

NICE Guideline on ME/CFS (2021)

All of these symptoms should be present for a diagnosis to be made:

- **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- **Post-exertional malaise** after activity in which the worsening of symptoms:
 - is often delayed in onset by hours or days.
 - is disproportionate to the activity.
 - has a prolonged recovery time that may last hours, days, weeks or longer.
- **Unrefreshing sleep** and / or **sleep disturbances** which may include:
 - feeling exhausted, feeling flu-like and stiff on waking.
 - broken or shallow sleep, altered sleep pattern or hypersomnia.
- **Cognitive difficulties** (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

People may experience other symptoms in addition to those listed above, and all symptoms will be experienced to varying degrees.

Common symptoms can include:

- Pain
- Nausea and vomiting
- Headaches
- Dizziness
- Palpitations
- Digestive problems
- Feeling drained / heavy
- An internal tremor / vibration
- Sore throat / painful lymph nodes
- Flu-like symptoms
- Sensitivities to noise, light, touch and smells
- Temperature dysregulation

Post-COVID Fatigue

The ME/CFS Service also provides support to people with fatigue related to Post-COVID Syndrome.

Rapid NICE Guideline for Post-COVID Syndrome (2022)

The guideline provides the following explanation:

- Signs and symptoms that develop during or after an infection consistent with COVID-19, **continue for more than 12 weeks** and **are not explained by an alternative diagnosis**.
- It usually presents with **clusters of symptoms**, often overlapping, which can **fluctuate** and change over time and can **affect any system in the body**.

Common symptoms can include:

- Fatigue
- Pain
- Sleep disturbances
- Breathlessness and / or disordered breathing patterns
- Palpitations
- Dizziness
- Cognitive impairment
- Headaches
- Nausea and vomiting and / or diarrhoea
- Abdominal pain
- Ear, nose and throat symptoms including tinnitus, loss of taste and / or smell
- Psychological symptoms.

What the ME/CFS service offers

We are a therapy-led service made up of experienced and specialised Occupational Therapists.

We provide our patients with strategies to help manage their fatigue, in line with the NICE Guidelines (2021) for the management of ME/CFS, and the Rapid NICE Guidelines (2022) for the management of the long-term effects of COVID-19.

The service is delivered via an educational online group programme and 1:1 sessions, supporting patients to feel more confident in managing their condition. We offer a time-limited service.

Self-management topics include:

- Understanding the condition
- Effective rest
- Activity management
- Sleep advice
- Cognitive impact of fatigue
- Stress management
- Impact of thoughts, behaviours and emotions on fatigue
- Communication
- Goal setting
- Managing setbacks and self-care planning
- We can also offer advice regarding employment and education

We also signpost to other specialist services such as Talking Health via Talkworks, Care Direct for equipment provision, or your local Community Rehab Team.



**Royal Devon
University Healthcare**
NHS Foundation Trust

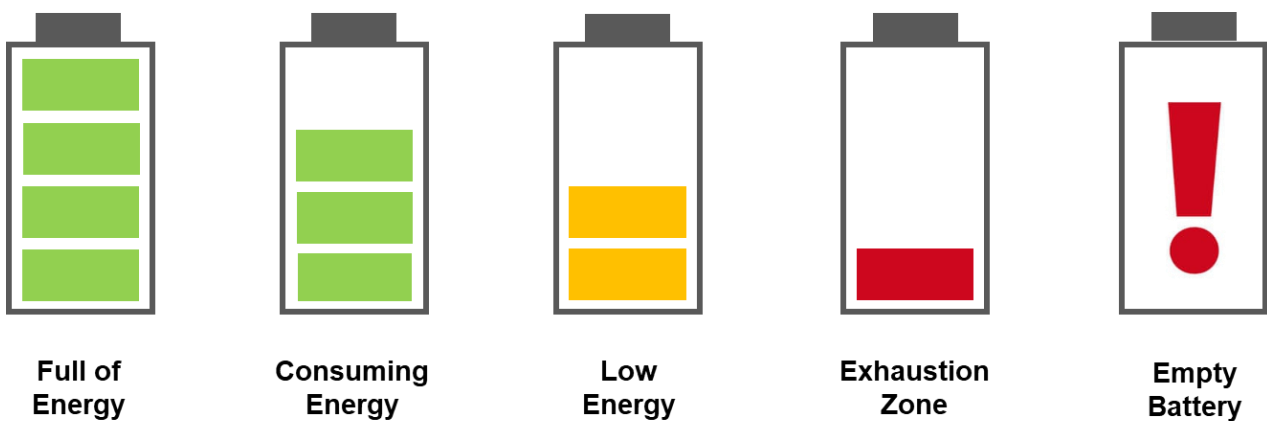
The Fundamentals of Fatigue Management



The human battery

A helpful analogy is to think about the body as having a human battery. Having conditions such as ME/CFS and Post-COVID Fatigue greatly reduces a person's battery capacity, and their ability to recharge effectively.

Many people find they start their day in the Low Energy zone because their battery does not reach 100% overnight.

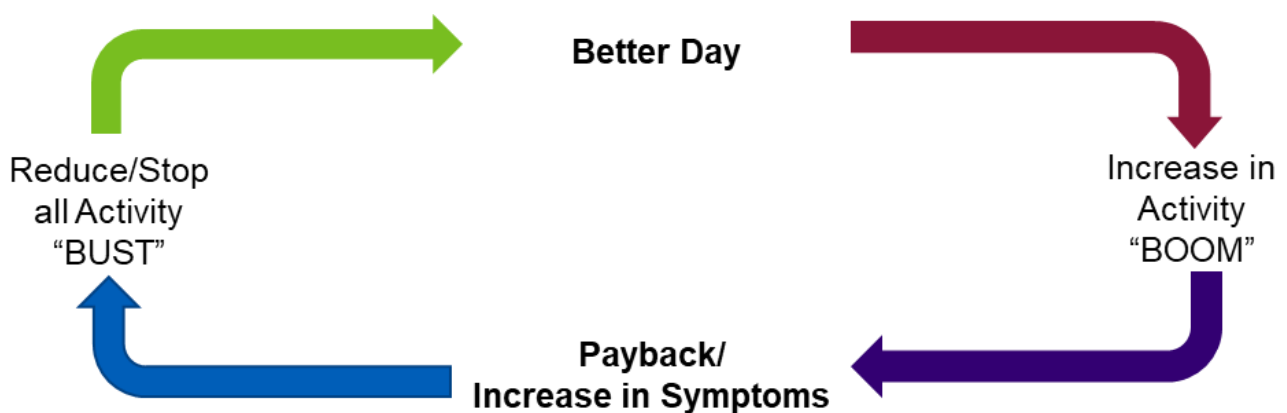


It is important to remember that all activities have an energy tag which depletes the human battery, whether they are physical, cognitive or emotional activities. Ask yourself what depletes your battery and what helps to top it up.

The over / under activity cycle

Most people with chronic fatigue find their energy levels will fluctuate. At times, they may feel they have a little more energy and as a result, engage in more activities. However, this can then lead to an increase in fatigue and subsequently, to longer periods of enforced rest.

This is the typical '**Boom and Bust**' pattern associated with chronic fatigue. The Boom and Bust pattern can occur over a day, a week, a month, or a longer period of time.

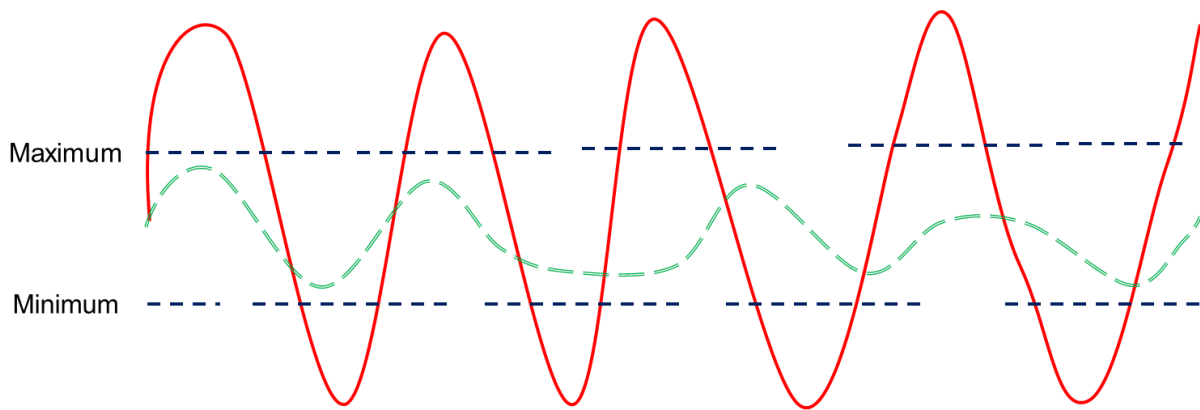





It is therefore important to establish a baseline level of activity that you can sustain. Going beyond your baseline of activity can also cause **Post-Exertional Malaise (PEM)**, which is an excessive level of fatigue or an increase in symptoms, usually experienced 24-48 hours after doing too much.

Finding your baseline can take time to establish because 'over activity' or 'excessive rest' will differ from one person to another. Your fatigue may still fluctuate, but by trying to keep within your baseline of activity, your energy levels may become more stable overtime.

Discovering your baseline of activity

Many people find it difficult to know where to start to find their baseline level of activity. Some carry out activities to their maximum capacity, or push through every day, which can cause an increase in symptoms or PEM. Others may limit the activities they do, which may help to stabilise symptoms in the short-term, but not over a prolonged period, and could lead to feeling 'stuck in the mud'.

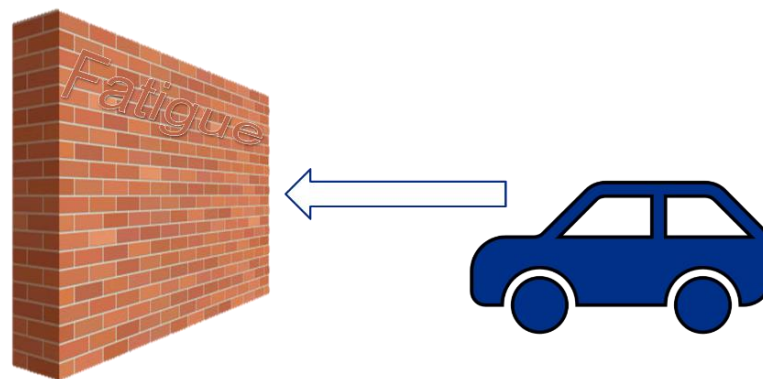


Key:	 Setting maximum and minimum energy levels
	 Energy use in a 'boom/bust' pattern
	 A pattern of optimum energy use = baseline level of activity

For those who find themselves in the boom and bust pattern of activity, the following analogy may be helpful.

Establishing a braking distance

Imagine a car's braking distance. Brakes need to be applied to allow time for the car to slow down, to avoid hitting the wall. An important part of fatigue management is recognising when to apply your brakes, to avoid hitting 'the wall of fatigue'.



When to apply the brakes

- **Early warning signs** (e.g. headaches, irritability, word finding problems)
 1. What early warning signs do you notice?
 2. Do you respond to these signs when you need to?
 3. Could you make further changes with this?

- **Setting time limits** (e.g. setting alarms or reminders)
 1. Do you set time limits on certain activities?
 2. Has this been helpful?
 3. Could you experiment with setting time limits for other activities?

- **Chunking activities** (e.g. reading one page or cleaning one room at a time)
 1. Do you break activities down into smaller chunks?
 2. Has this been helpful?
 3. Could you experiment with chunking any other activities?

Using activity diaries

We encourage you to complete your own activity diary as they can be very helpful to:

- Recognise helpful or unhelpful activity patterns, such as boom and bust.
- Recognise what activities deplete or top up your battery.
- Help establish realistic routines for activity e.g. sleep, rest and mealtimes.
- Find opportunities for helpful change.

A useful first step to starting an activity diary is to give some thought to the energy demands required for all the things you do.

To achieve this, consider whether a task involves a **high energy** expenditure (drains your battery quickly) or a **low energy** expenditure (drains your battery more slowly).

In addition, it is important to consider the emotional or cognitive demands of a task or situation, as these may also cause your battery to drain more quickly.

Consider using a chart to help categorise your activities before putting them on your diary (blank chart is included at the end of the pack).

Example activity demand chart

Activity	High	Low
<i>Examples:</i>		
<i>Showering</i>	✓	
<i>Washing Up</i>		✓
<i>Paying Bills/ paperwork/ phone calls</i>	✓	
<i>Watching TV / Scrolling on phone</i>		✓

Effective rest

Effective rest is an essential part of activity management as it allows you to conserve your battery. It can support you to recharge physically and mentally, and potentially reduce the need for daytime sleep. Research shows that it can also help you to manage stress more effectively and strengthen your immune system.

Rest is most effective when both mind and body are as calm and relaxed as possible.

The boom and bust pattern of activity can result in periods of enforced and unplanned rest, which can be very frustrating. Planning and scheduling effective rest, as part of your daily activity management, can help you pace your activities throughout the day. This helps you feel more in control by avoiding those periods of boom and bust.

Rest analogies

There are two useful analogies we use in the service that can help you give yourself permission to rest.

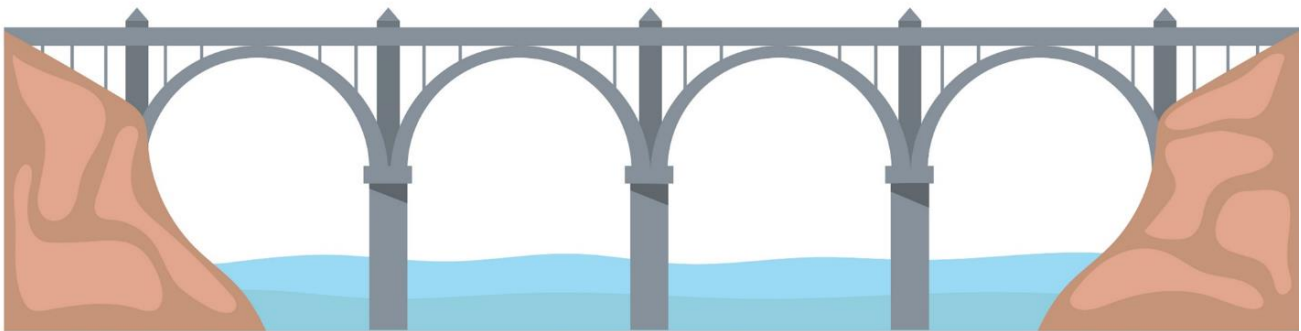
The first analogy is to think about rest being a **'Prescription'** that you plan and take regularly to help you manage your fatigue.



The second analogy is to think about **'Pillars of Rest'**.

Imagine your day as a bridge of activity. If you only had a pillar (such as sleep) supporting the bridge at the beginning and at the end of the day, it would collapse in the middle.

Now imagine your day as a bridge with regular pillars of effective rest. These pillars, together with night time sleep, help support your energy levels and engagement in activities consistently throughout the day.



It is helpful to give yourself permission to plan 'Pillars of Rest' and explore what 'effective' rest means to you.

Not planning or taking your 'Pillars of Rest' may lead to prolonged periods of unplanned and enforced rest, which can perpetuate the boom and bust cycle.

Top tips for effective rest

- Explore a variety of techniques and resources to find a few that work for you.
- Techniques vary and encourage you to focus on your senses, your body, and / or your breathing. Visualisation can help the mind focus on positive scenes and experiences.
- Practices can be done lying down or sitting in a supportive chair.
- Find a space which is warm and comfortable for you and minimise distractions.
- See rest as an activity in its own right.

Ideas for effective rest

Visualisation

Breathing techniques

Relaxation exercises

Very quiet music

Simple meditation practices/mindfulness



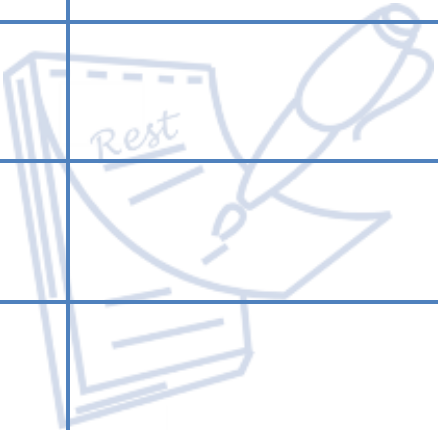
Using the senses

Use of Apps e.g. Insight Timer, Headspace, Calm, BBC Sounds

It might be helpful to discuss with your family and friends how they can best support you to make time and space for your effective rest.

Rest and Relaxation Diary

Date	Time	What did I do to rest / relax?	How did I feel afterwards?	Comments



Resources for rest and relaxation

Sitting Relaxation with Desensitisation Techniques

The following practices are based on Yoga relaxation and pre-meditation practices. They have been widely used in Mindfulness and Stress Management programmes all over the world.

It is recommended that you first practice them at home. When you are more familiar with the practices, you can transfer them into every-day situations, such as when sitting in a waiting room, on a bus or train, or just after parking the car before your next activity. They should take between 5 – 10 minutes.

Posture:

- Sitting in a chair, head supported if possible, eyes closed or gaze lowered.

Developing awareness of the sensation of *touch*:

- Soles of feet on floor – sense contact between feet and floor / weight / firmness
- Thighs against seat – sense contact / pressure / weight
- Back against chair – sense contact / pressure / weight
- Hands resting on lap – sense contact against legs / weight
- Sense texture of clothing / seat
- Face – skin in contact with air – sense temperature / movement or stillness through skin
- Eyelids – sense weight of eyelids over eyes / resting

Developing awareness of the sensation of *sound*:

- Detect sounds – close by / far away
- All sounds / noises in room / outside
- No need to analyse
- Listen
- Witness
- Listen to one sound, then another
- Listen to all sounds together
- Then bring awareness into the body – listen to the sound of your own gentle breathing

Breathing Practices for Everyday Life

Effective breathing makes more efficient use of the lower part of the lungs (often called ‘the abdominal or diaphragmatic breath’).

If you watch a baby or a pet dog / cat sleep, you can watch its tummy move up and down as it breathes. We were all excellent abdominal breathers as babies, but often unlearn the ‘right breathing’ as we go through life. We might have formed a habit of holding tension in our tummies and then pushing the breath into the upper chest.

It is useful to re-learn abdominal breathing for the following reasons;

- ✓ It increases the oxygen supply to the body, has a calming effect on the nervous system, and is needed to help us fall asleep.
- ✓ It can see us through challenging situations, by keeping a stress and / or anxiety response at bay.
- ✓ If you experience a stressful time you can also use this breathing technique to calm the system down again.
- ✓ Last but not least, it helps us to be more assertive when we need it!

Posture:

- To start with, it is advisable to develop your breathing practice lying on your back, with a flat pillow under your head.
- If you experience lower back problems, bend your knees and support them from underneath with cushions or a blanket rolled up.
- Let the arms rest by the sides and a little away from the body. Initially, you might wish to rest one palm across your tummy.
- Later on, you can practice in many situations of daily life, like when standing in a queue, when stuck in traffic, or – once you are a pro - during an argument!

Breath Awareness:

Before you work on the abdominal breath, it is important that you spend 5 – 10 minutes watching the natural spontaneous breath first. This alone will calm the breath and, subsequently, the nervous system down. You will discover this yourself, as your breath will become longer and less frequent, and you begin to feel more relaxed.

Long Out Breath:

- When we want to increase the efficiency of our breathing and the amount of oxygen available to us, we need to increase our out breath. This is because there can be a lot of unused oxygen in the lungs, and we want to increase efficient usage.
- First watch the natural breath for about 10 breaths.
- Then begin to deepen and lengthen the out breath.
- Let the breath in follow naturally with minimal effort.
- Imagine and visualise a long line from the crown of the head all the way down to the feet.
- Start breathing out the line of the body. Imagining a downward, sweeping movement as you breathe out.
- Develop a sense of awareness, a sense of letting go as you breathe out.

Abdominal Breath

- First watch the natural breath for about 10 breaths.
- Then take your awareness to the navel and the area around it (the abdomen).
- You might discover a slight rising and falling as you breathe in and out.
- Focus your attention on each in breath and each out breath. If your mind wanders gently bring your attention back to your breath.

You may notice a gradual deepening of the breath, taking your time, no forcing;

‘I am breathing in – I am breathing out.’

Activity diaries

Activity diaries are used for:

- **Monitoring / recording** current activities, rest and sleep
- **Identifying** patterns of Boom and Bust
- **Planning / modifying** activities and setting a baseline
- **Measuring** progress

What's on the activity diary?

- Space for name and date at top
- Shows one week per page
- Days of the week are in left hand column
- 24 hours along top row – starting at midnight through the day to midnight again. Each box represents one hour. You can divide the boxes up if you wish to.
- Day Score – Score how fatigued you feel each day on a scale of 1-10.
1 = worst day ever, 10 = best day ever.
- Key at bottom; choose five colours – one colour for each item:
 - **High Activity:** Any activity that drains your energy quickly.
 - **Low Activity:** Any activity that drains your energy, but more slowly.
 - **Rest:** A state of resting both mind and body. Note that watching TV or reading would not be classed as rest.
 - **Sleep:** Overnight or daytime.
 - **Restless Sleep:** Tossing and turning in bed.

Completing the day score

- Complete the day score at the same time each day.
- Scoring ranges from **1** for your best day through to **10** for your worst.
- Base your score on how you feel at that same time each day - at that moment - NOT how much you have done that day or what your mood is like.

Completing the diaries will help you to:

- identify patterns of energy use, especially Boom and Bust
- introduce strategies such as pacing and Pillars of Rest
- monitor your progress
- forward plan

Example activity diaries are included, with two blank diaries for you to use.

ACTIVITY, REST & SLEEP DIARY – demonstrating a BOOM & BUST pattern of activity

Name: Joe Bloggs

Week beginning: 24th April

	Morning (am)												Afternoon and Evening (pm)											Day Score 1-10			
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10		11		
Mon	Sleep							Restless sleep	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	Low Activity	Low Activity	Low Activity	Low Activity	Sleep					
Tues	Sleep							Restless sleep	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	Low Activity	Low Activity	Low Activity	Low Activity	Sleep			
Wed	Sleep										High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	Low Activity	Low Activity	Low Activity	Low Activity	Restless sleep	Restless sleep			
Thurs	Restless sleep	Restless sleep	Sleep										High Activity	High Activity	High Activity	High Activity	High Activity	High Activity	Low Activity	Low Activity	Low Activity	Low Activity	Restless sleep	Sleep	Sleep		
Fri	Sleep		Restless sleep	Restless sleep	Restless sleep	Sleep							High Activity	High Activity	Low Activity	Low Activity	Sleep				Low Activity	Low Activity	Low Activity	Low Activity	Sleep		
Sat	Sleep	Restless sleep	Restless sleep	Sleep					Restless sleep	Restless sleep	Sleep				Low Activity	Low Activity	Low Activity	Low Activity	Low Activity	Low Activity	Low Activity	Low Activity	Restless sleep	Restless sleep			
Sun	Sleep				Restless sleep	Restless sleep	Sleep					Low Activity	Low Activity	Sleep				Low Activity	Low Activity	Low Activity	Low Activity	Low Activity	Restless sleep	Restless sleep	Sleep		

Key: High Activity ■ Low Activity ■ Rest ■ Sleep ■ Restless sleep ■

High Activity: drains energy quickly
Low Activity: drains energy more slowly
Rest: resting your mind and your body

Sleep: sleeping soundly
Restless sleep: is the intention to sleep but maybe disturbed by pain, thoughts, noise

Score: Complete the score at the end of each day. 1 (worst day) – 10 (best day)

This diary shows a pattern of **BOOM & BUST**. The start of the week shows long bouts of **HIGH** activity, followed by **LOW** activity and **SLEEP**. As the week progresses “payback” sets in and the person is less and less able to carry out activities, until at the weekend they have to **SLEEP** most of the time. There is no sleep pattern, getting up time is getting later and later. If this pattern continues symptoms are likely to worsen and the condition will be prolonged.

Date:

		/			/	2	0		
--	--	---	--	--	---	---	---	--	--

