

CFS/ME Foundation Phase Workbook 1



Contents

What is CFS/ME?

What causes CFS/ME?

Approach used by CFS/ME Service

Activity Management and Pacing

The Activity Cycle – “Boom and Bust”

How can this ‘boom and bust’ approach to activity be changed?

What is Pacing and how can it help?.....

What pacing is NOT about

“Stop rules”: four different ways of knowing when to stop an activity.....

Baselines - knowing when to stop, to avoid the activity cycle ...
.....

One Way of Setting a Baseline: the” 50% rule”

Activity levels



What is CFS/ME?

The main symptom of CFS/ME is a mental and physical fatigue which feels different from normal tiredness.

Along with this are a range of other symptoms which can include:

- headaches
- widespread muscular and/or joint pain
- sleep disturbance and unrefreshing sleep
- difficulties with concentration and memory (“brain fog”)
- feeling fatigued and ill after activities
- sore throats and tender glands
- dizziness and balance problems
- odd sensations like pins & needles and numbness
- sensitivity to light and noise
- digestive disturbance

Different people experience some symptoms more than others. For example, pain can be a big problem for some, and not for others. The condition affects people in different ways: some people are mildly affected, moderately affected, or severely affected. Some people have setbacks or relapses, other people are more stable.

What causes CFS/ME?

We often meet people who have developed CFS/ME following an infection, such as glandular fever. Other people have identified a significant amount of stress, or many stressful situations occurring together, or a long period of stress, which is thought to increase the odds of developing CFS/ME. A combination of an infection and stress is commonly reported. Occasionally, it seems to come “out of the blue”.

Researchers are beginning to put together a picture about how the condition develops and the changes which take place in the body as a result of illness, but the exact mechanisms underlying CFS/ME are still unknown. Our current understanding is that the immune system and the nervous system are likely to be involved in CFS/ME. It is possible that the potential to develop CFS/ME may be partly connected with our genetic makeup. When an individual develops CFS/ME their external appearance does not usually change. This sometimes leads people who do not know anything about CFS/ME to conclude that it is a psychological problem. CFS/ME is not a psychological condition, but what we think and how we respond physically in this situation can influence the course of the illness in a helpful or an unhelpful way.

With CFS/ME the body’s systems are said to have become poorly regulated and hypersensitive. The body is in a constant state of “high alert” almost as if a switch has been thrown and the whole system is in a state of emergency. This is thought to be why the smallest of stresses such as noise, light or physical activity can have a big impact on the symptoms of CFS/ME.

Approach used by Bristol CFS/ME Service

Our Service aims to help patients and their doctors to identify the condition, and then offers support to manage it as effectively as possible.

This manual is put together to accompany our “Foundation Phase” CFS/ME self-management group. It also supports the individual work done between one of our clinicians and a person with CFS/ME who is trying to improve their management of the condition. The manual covers a wide range of issues which are important to our patients. You will need to work with your clinician to work out the best self management strategies for you and your particular situation.

Activity Management and Pacing

These are some of the consequences of having CFS/ME which our patients report:

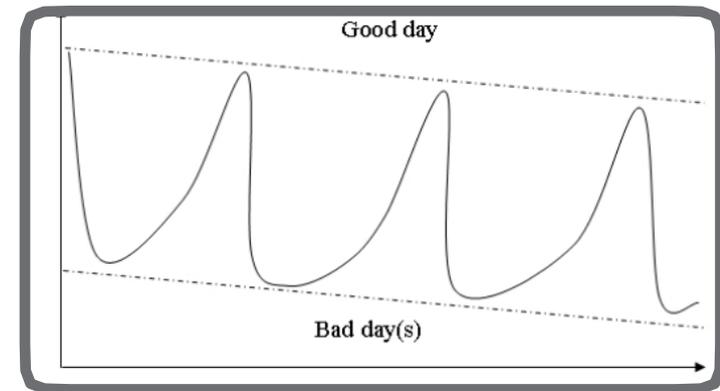
- it's hard to plan
- paid work, voluntary work and housework are affected
- it can be hard to get refreshing sleep
- it affects relationships with family and friends
- physical activity is reduced
- it's hard to concentrate for work and study
- pleasurable activities are often stopped

Planning can be difficult because “ups and downs” in the condition are common.

The Activity Cycle – “Boom and Bust”

People with CFS/ME often describe having varying amounts of fatigue from one day to another or even within the same day. This can make it difficult to decide whether or not to attempt an activity. Most people tend to do more when they feel a bit better and not as much when they feel unwell. You may find that you “overdo it” one day and then have several days recovering. This can lead to big swings in activity over time: this is known as the “boom and bust” approach or “activity cycling”.

The graph below shows the “ups” of increased activity, and the “downs” of the recovery phase.



The signals that the body produces can be an unreliable guide as to what we should or should not be doing “in the moment”. This is very different from more recent or “acute” illnesses such as having a stomach bug. With an acute infection, the body reacts by making us feel unwell so that we rest more. When we feel better this is a sign that the illness has passed and we can get going again. CFS/ME is different to an acute illness: listening to the body on a moment-by-moment basis to decide what we should or shouldn't do is often unreliable. On days when you feel slightly better it is not necessarily a sign that the illness is passing. A different set of tactics is needed to manage CFS/ME effectively.

How can this 'boom and bust' approach to activity be changed?

- Recognise that this is how you tend to approach activity.
- Keep records such as an activity diary, this helps you to work out your baseline, and any planned increases later on. See section below on activity diaries.
- Analyse how much of an activity you can do on a good day and a bad day. Find a manageable level you could sustain: a similar amount each day. In practice, this will usually mean that you set a baseline of activity which is starts out being lower than you would normally do on a good day. See section below on setting baselines.
- Balance periods of activity with regular short rests. See section below on pacing.
- Set realistic goals to help bring about change. You can discuss goalsetting with your clinician in your individual appointment.

What is Pacing and how can it help?

Pacing is all about balancing daily activity and rest to get control over a "boom and bust" pattern. The word 'activity' is used in a broad sense, to include mental and emotional activity, as well as the more obvious physical sort. Pacing is also known as "activity management".

To understand pacing, it can be helpful to think of your available energy as being like a mobile phone battery:

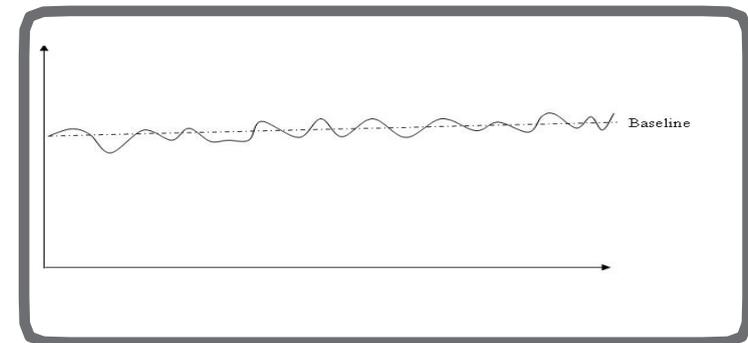
- If you completely drain the battery, you have to wait to recharge it before you can use the phone again.

OR

- If you use some of the battery and make regular top-ups, then your phone will always be ready for use.

Before you start pacing you need to keep a record of your activity levels. You then need to decide on a baseline level of activity which you could do day after day, all things being equal. You would then try and keep your activity close to your baseline level. This will mean "holding back" on a better day. By holding back on a good day, you should have fewer bad days, and life becomes more predictable. There may still be some ups and downs with symptoms, for a range of reasons, such as poor sleep.

Pacing gives you awareness of your own abilities and limitations, which enables you to plan the way that you use your energy, prioritising what you can do with it. The graph below shows how pacing can provide a stable foundation of activity to build up from.



Many people have setbacks, when their symptoms get worse for a period of time. We advise people to 'pace down' during these times, and work to a lower baseline. People can then gradually 'pace up' again as they recover from the setback. This is like moving up through the gears of a car, rather than jumping straight into fourth gear on the first good day after a setback. We have a separate information sheet about managing setbacks.

Over a period of time, when you can consistently manage your baseline level you can plan to slowly increase. Some people call this increase in activity 'graded activity'. If the approach is used for a physical activity like walking, it is called 'graded exercise'. It is also sometimes simply called 'pacing up'.

What pacing is NOT about

It can be as important to understand early on what pacing is not about. It does not give you a free hand to push through activities, with enforced rest and recuperation (also known as “crashing”) afterwards. Pacing takes an altogether smoother approach:

- If you are prone to trying to cram in as much activity as you can in the morning, then have to rest during the afternoon or the next day to recover, pacing helps you to break this habit.
- Similarly pacing discourages you from gathering energy through the day and then attempting a burst of activity later in the afternoon or evening.

Having said that, one of the advantages of knowing your baseline levels for different activities is that you know beforehand when you are likely to “overdo it”. This helps if you are likely to be overdoing it because you need to, or because you want to. You then know that you are likely to need to rest more afterwards and can make arrangements. This knowledge increases the amount of control you have over situations.

“Stop rules”: four different ways of knowing when to stop an activity

There seem to be four main ways that people use to know when to stop activities. It is worth knowing about these “stop rules”, so that you can learn which one you use most of the time. You may then choose to use other “stop rules” to get more control.

1. “Fighting it”. This is somebody who tries to carry on with activities until their symptoms become so intrusive they have to stop. They “hit the wall”. They may say: “I won’t let it beat me: I carry on until I have to stop”. In this situation, they rely upon severe, intrusive symptoms to tell them when to stop activities. This person is more likely to fall into the Activity Cycle trap. However, they may get more done in the short term.

2. “Listening to my body”. Some people notice a gradual increase in symptoms, which they start to identify as warning signs to stop. They will stop their activities sooner than somebody who is “fighting it”. They may say: “I listen to my body: it tells me when to stop”. This person is less likely to fall into the Activity Cycle trap, if they are able to notice the warning signs in time. One of the downsides of this strategy is having to pay regular attention to these symptoms to watch out for the warning signs.

3. “Time-contingent pacing”. Using this stop rule, people learn from experience how long they can successfully manage an activity for. They may use a diary to work out what they can manage sustainably, day after day. They may say: “I keep an eye on the clock, because I know my limits. That way, I have some energy left for later”.

4. “Activity-contingent pacing”. Using this stop rule, people learn from experience how much of an activity they can manage successfully. They may say: “I can iron two shirts, then I have a rest, even if I feel I could do a third one straight away”.

Think about the four ways of knowing how to stop. Which one do you use more often? What are the “pros and cons” of the different stop rules? Remember, CFS/ME symptoms usually feel worse a day or two after activity, so they are often not a reliable guide as to when to stop.

Setting a baseline uses either the third or fourth stop rule. An amount of time or activity is worked out that can be used as a guide to know when to stop.

Baselines - knowing when to stop, to avoid the activity cycle

- Find a low level of activity that you could manage on a daily basis: this is your “baseline”.
- Aim to keep your activity at your planned baseline level: don't be tempted to do more on a good day.
- Aim to do the activity on most days to avoid falling into the Activity Cycle trap. Establish a routine.
- Use a recording system to allow you to keep track of your baseline, until it becomes “second nature” to be aware of it.

One Way of Setting a Baseline: the” 50% rule”

- Start by trying an activity at a level that you think you will cope with easily. Don't feel that you need to push yourself to achieve your “personal best”.
- Record your achievements.
- After three days, work out the average that you have managed. Then decide whether you will realistically manage to keep up this average; if not you may need to lower your sights, perhaps reducing your baseline to 50% of the average.
- Remember: you are aiming for a sustainable level which can be built on to gain medium and long term improvements, not a quick change!

Setting a Baseline: using a chart to calculate your baseline

Try using this chart to record and work out your baseline for walking, to learn how the charting system works. There is room on the chart for you to work out a baseline for other activities which are important for you (e.g. reading, computer use, social activities).

Activity:	Example	Walking			
Day 1	4 minutes				
Day 2	4 minutes				
Day 3	5 minutes				
Total of 3 days	13 minutes				
Total / 3 = Average	4 minutes				
Baseline (half of average)	2 minutes				

Now you have worked out your baseline, aim to stick to it until you are confident that your baseline is manageable. Record your achievement in the table below, and make up your own table to continue your record.

	Example				
Day 4	2				
Day 5	2				
Day 6	2				
Day 7	2				

Activity levels

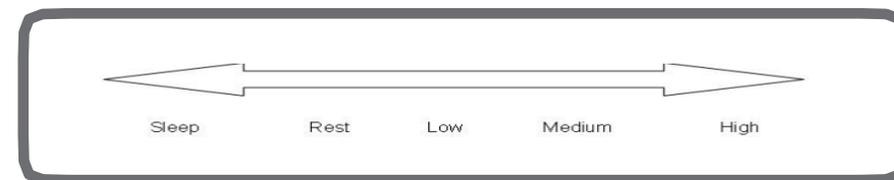
Activity levels can be analysed by being aware of the amount and intensity of energy required. It can be helpful to think of activities arranged along a line with sleep and rest at one end and high energy activities at the other. Balance is required

- how would you feel if a day consisted of entirely low and restful activities? Or if they were all high? If you do have a day like this what happens? Many people report that this is what the boom and bust cycle feels like - a day or days or a part of a day doing high level activities then a long time recovering and only being able to do low or restful activities.

It can be helpful to know what activities you find restful, low

demand, medium and high demand, and try and get some

balance between the different levels. You can use this awareness to plan your day or your week so that the activity types are spread out.



This workbook is the first of two. The second workbook focuses on sleep, recuperative rest, and stress management. Both of these workbooks suggest trying out changes in the way that you manage your CFS/ME, but we also know that these changes can be difficult to make. If you are finding it difficult to put any of these strategies into place, please discuss this with your individual clinician. This will usually be the clinician who assessed you.

A patient's story

One of our patients has kindly agreed to be videoed talking about her story. Her name is Meline. In the video, she talks about the symptoms that she had and the difficulties they were causing in her day-to-day life. She also describes the strategies that helped her to gain more control over her CFS/ME and make progress with her goals.

We thought that it may help you to listen to Meline's story, particularly if you have recently been diagnosed and are in the early stages of learning about CFS/ME.

The video is available from the North Bristol NHS Trust website. To access the video, just type the following address in the internet address bar (not the search bar) at the top of your browser: **www.nbt.nhs.uk/melinesstory**

NHS Constitution. Information on your rights and responsibilities: **www.nhs.uk/aboutnhs/constitution**

**PATIENT
APPROVED** 

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 **www.nbt.nhs.uk/CFSME**

If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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