



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

Self-help information for patients

What this self help pack aims to do

This booklet has been put together as a resource to enable you to begin looking at areas of your life you may be able to adapt, to help with the day to day management of your CFS/ME.

We hope that this pack will give you some initial basic practical guidance on how to manage your CFS/ME more efficiently.

Please take your time to read each section as there is a great deal of information to absorb. If you have any queries or concerns regarding this information please contact the Greater Manchester Clinical Network Co-ordinating Centre (CNCC) for CFS/ME on 0161 219 9420.

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Introduction

There are a number of specialist CFS/ME services across Greater Manchester which aim to help people deal with and reduce the difficulties that are associated with CFS/ME.

Following a referral and initial assessment, the specialist team will work with you to create an individual management plan to help you lessen the impact of CFS/ME, and gradually improve. The team will also work closely with your GP and any other health professional who may be involved in your care.

This information booklet provides information for adults about this condition.

If you are unsure how to contact your local CFS/ME service please contact the CNCC for CFS/ME for further information.

How to contact us

We are happy to receive your feedback about this booklet or our services by any of the following methods:

Tel: 0161 219 9420

Post: Manchester Clinical Network Co-ordinating Centre for CFS/ME,
Silk House,
Newton Heath,
Manchester,
M40 1HA.

Web: www.manchestercfsme.nhs.uk

If you would like any further information about the CFS/ME Services in Greater Manchester, please contact us using the details above.

What is Chronic Fatigue Syndrome/ME?

This information has been put together by the CFS/ME Team to help you understand what CFS/ME is and how it affects you. The pack will also hopefully help you to control the symptoms of the condition. We will use some comparisons to describe the factors that influence your fatigue and hopefully show you that you do have some control over your symptoms

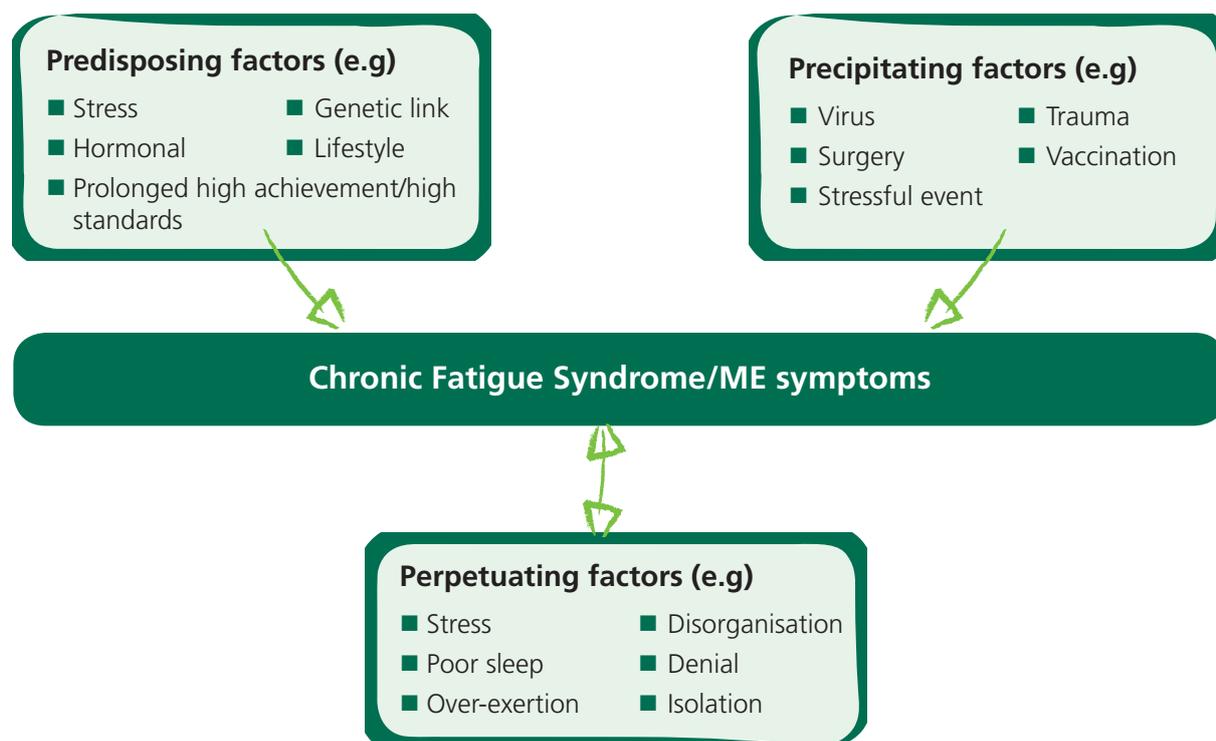
Myalgic Encephalomyelitis (ME), Post Viral Fatigue Syndrome (PVFS), and Chronic Fatigue Syndrome (CFS) are some of the names used to describe a syndrome, which is probably a similar type of condition and whose main feature is excessive fatigue.

Chronic Fatigue Syndrome/ME is the preferred term used in this information. It more accurately describes the illness and is now officially recognised. CFS/ME affects people in different ways and no two people experience the illness in the same way. The main feature is persistent physical and mental fatigue, which differs from normal tiredness. It is not adequately relieved by rest and is usually out of proportion to the activity undertaken.

A range of other symptoms often accompany the fatigue. These include muscle and/or joint pain, headaches, swollen glands and recurring infections – often sore throats. Some people have feelings of dizziness and temperature fluctuations. There are frequently some difficulties with memory and concentration and many people experience problems with their sleep. They often have vivid dreams and wake feeling unrefreshed. Many people describe sensitivity to some foods and medicines.

Currently there is no specific diagnostic test for CFS/ME. However, there is a clear protocol that is used to confirm the diagnosis. A diagnosis is made by excluding around 40 other conditions that cause fatigue. Your GP will have arranged a variety of blood tests, liver function tests and routine biochemistry tests prior to attendance at the clinic.

Below is a model of CFS/ME that can be used to explain some reasons why CFS/ME develops and how the condition is maintained.



'Boom and bust'

Flat batteries

Imagine that you have energy very much like that of a battery. When you participate in an activity, this energy will get used up and, in the average person, will fluctuate according to the demand made upon it. Normally, rest will enable the battery to recharge fully.

With people with CFS/ME, however, this is not the case. It appears that the battery, for some reason, has become completely flat. There is literally nothing there: your battery is 'drained'.

So the natural thing to do is obviously rest. The average person, after resting, would experience a fully recharged battery. Unfortunately, with CFS/ME it appears that no amount of rest will fully recharge the battery. Any recovery of energy will be small, but the person with CFS/ME has at long last got some energy!

They then may tend to think "Well I'm better now so I had better get on and do all the things that I have neglected to do whilst resting, and there's all the housework and other things that I should have done before and couldn't manage, well now I can!" Unfortunately, as only very little energy has been recovered in their battery, this is swiftly used up and the individual then experiences a flat battery all over again.

This is also known as the BOOM AND BUST experience. Your energy fluctuates, and on the days when you have more energy, you have a boom of activity and then have to rest in the days following to recover energy. This boom and bust pattern becomes a vicious cycle that perpetuates your CFS/ME. Guilt is often a factor which pushes the individual to try and make up for the resting and do more on a good day. Your behaviour can be the very thing that is perpetuating the condition and preventing improvement.

The good news is that as long as you are ready to change your behaviour, you can stop the vicious cycle of boom and bust.

Energy overdraft

Another analogy that is useful to consider is that of the energy overdraft. Try to consider your energy as a valuable commodity like money, which needs to be looked after. Would you throw your money away on a whim? Why not try to be thriftier with your energy?

What you need to do is imagine that you have a massive overdraft of energy, so that even on your good days, there is still a need to save energy to pay off the overdraft. This makes you value the energy that you do have.

You now need to plan out your days to ensure that you will not do too much on the 'good' days so that you are able to pay back your energy overdraft. It's quite simple: bear in mind that **YOU STILL HAVE CHRONIC FATIGUE/ME EVEN ON YOUR GOOD DAYS!** Your recovery is dependent on your behaviour and your energy expenditure on both good and bad days.

Also, consider the things that you like to spend your money on. This same principle applies to spending energy. You want to get the best 'value for money' from your spending of energy, yet you are spending it on mundane chores and things that you feel you have to do or should do. This can make you feel a bit resentful, especially in CFS/ME where the energy is so sparse.

Pleasure equals energy

Think about a couple of scenarios. Those of us who have ever been in love will recall the energy that was created by that experience. Even though there were sleepless nights and lots of late nights, somehow you managed to bound into work, running around doing all sorts of things with bags of energy to spare...well how come?

What a lot of people fail to recognise is the powerful link between the way you feel emotionally and the effect that this can have on your body and how you feel physically. This is an important factor in CFS/ME.

Emotions are so strong that they defy any logical explanation at times. Take another example – Monday morning. Why is it that most people admit to having difficulty getting up and going to work? You've just had a weekend of relaxing and lying in and yet you still feel tired. Yet come Friday morning and you almost leap out of bed, despite having a stressful and exhausting week leading up to this. The physical demand of this situation has no bearing; rather it is more to do with how you are thinking and how you are feeling emotionally.

In light of this, we advise CFS/ME patients to start to reintroduce all the pleasure items back into their lives. Previously you would have taken it for granted that you could do these things on top of all your other responsibilities. Don't feel guilty about engaging in the 'nice' stuff.

YOU NEED TO PRIORITISE PLEASURE IN YOUR LIFE!

Consider these points....

- Have you found that you have lost a lot of friends?
- Have you felt that your partner is getting fed up or that there is a rift since you became unwell?
- Do you find yourself resenting spending energy on certain tasks to the point where you become irritable and bad-tempered?

Being out and having a nice pleasant experience or having an immaculate house – what is more important? What if you had had a stroke – would you feel so guilty for not being able to maintain your high standards then? It is not your fault that you have become ill, but you do need to look after yourself. Pushing yourself to maintain your standards will only make you worse.

New agendas

You may have to face the fact that the very person that you were before your illness has contributed to your getting CFS/ME, in much the same way as being prone to stress can contribute to heart attacks.

You will now have to change to an extent that will allow you to maximise the energy that you have and achieve a better quality of life. You may never go back to rushing around doing 10 things at once and if you do, there is the likelihood that you will bring on your CFS/ME again.

The secret is to find new ways of behaving that are not too frustrating but that give you back the control to your life.

Taking to bed

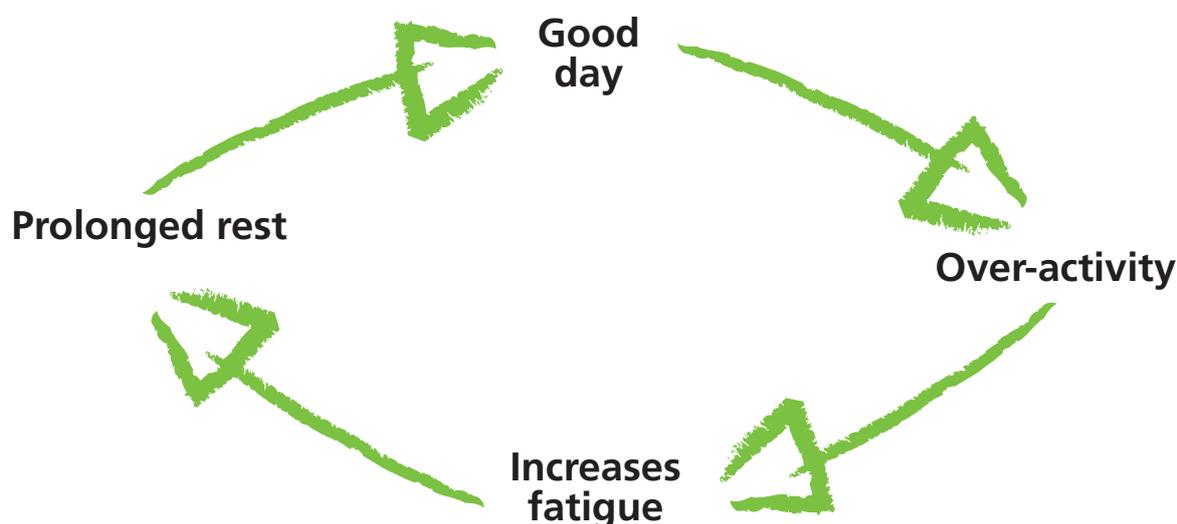
When the body over-rests, particularly when lying down, muscles can start to become weak and they go through a process of de-conditioning. This process is similar to someone who has been going to the gym and then suddenly gets flu and is laid up in bed for a few weeks. Not surprisingly, when they return to the gym, they cannot manage the level of exercise that they did prior to being unwell. If the person eases themselves back into their routine they should be able to return to their previous level of fitness.

In CFS/ME, however, the exercise is actually your general daily activities, and if your body has been resting for a considerably long time, it may have experienced some de-conditioning. Your body may have, through rest, become weaker; muscles start to lose their bulk. Thus returning to your previous activity levels can feel very difficult. You need to build up your tolerance again.

We are not suggesting that you do not rest at all, but do consider the adverse affects of taking yourself to bed for long periods of time. De-conditioning can make your CFS/ME seem worse. The most important thing is to establish a routine that will allow for a balance between activity and rest, and some consistency in your routine. You want to aim for a slow increase in your activity levels over time, without an increase in your fatigue.

The activity cycle

Often people with CFS/ME describe having varying amounts of energy from one day to another or even within the same day. A lack of control of this energy may be experienced with an inability to forecast whether or not to attempt an activity. This lack of energy may lead people to attempt to do too much on a better day and then spend several days recovering from it. This is referred to as the boom and bust approach or activity cycle:



The problem of staying in this activity ('boom and bust') cycle is that every time you overdo it you are more likely to avoid doing these activities in the future.

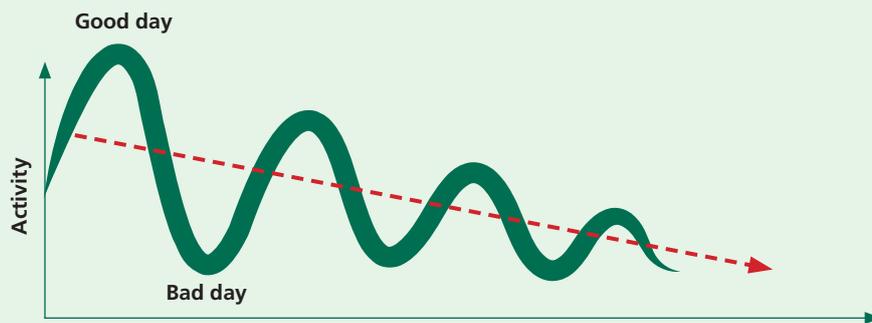
Q. How can this 'boom and bust' approach to activity be changed?

- Acknowledge that this is how you tend to approach activity.
- Start to analyse how much of an activity you can do on a good day and a bad day, the aim being to sustain the same amount each day. In practice, this will normally mean that you set a baseline of activity which is initially lower than you would normally attempt on a good day.
- Balance short periods of activity with regular short rests. See information on pacing.
- Keep an activity diary, paying attention to which activities are high on energy requirement. Try and spread these out over the day.
- Set realistic, tangible goals to help bring about change. See information about SMART goals approach.
- Keep records of your achievements, no matter how small. This will show you that pacing yourself throughout the week is preferable to waiting for a good day to do too much then 'crashing' for the other days.

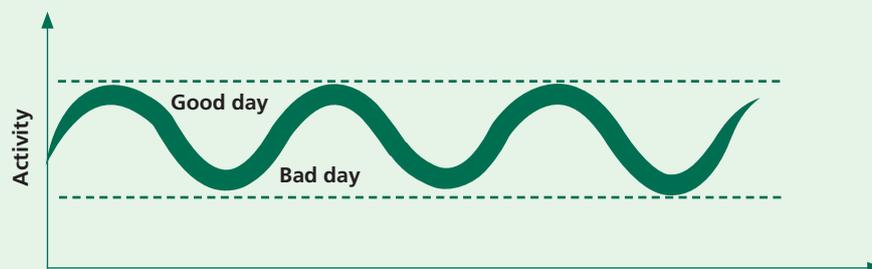
Pacing

Pacing is the way all of us should balance our daily activity. It is especially useful if you have CFS/ME as your energy stores are much lower and therefore balance becomes even more important.

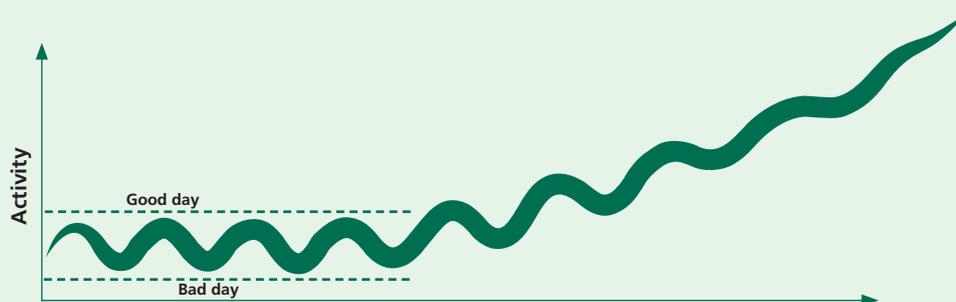
Most people tend to do a lot when they feel good and not very much when they feel unwell. This can lead to big swings in activity and if you have CFS/ME you may find that you over do it one day and then have several days recovering. The idea of pacing is to stop this swinging from one extreme to another so that you can start the process towards recovery.



Before you start pacing you need to keep a record of your activity levels. You then need to decide rough maximum and minimum levels of activity which you will be able to do on good days and bad days. For example this might be three hours of work on a good day (and this would probably feel too easy but you would keep your reserves up) and one hour of work on a bad day (would feel tough but would be possible). You would then try and keep your activity between these limits on good days and bad days.



Over a period of time you will find that you can gradually increase these levels on both good days and bad days as you are storing up energy. Some people call this increase in activity 'graded activity' but for many people this will happen naturally as you get better.



Setting goals

Q. What are goals?

Goals are clear statements of your own ambitions, and will vary from person to person. Some examples of different people's goals are:

- Walking to the local shops three times a week
- Managing to vacuum a room
- Meeting a friend for a chat
- Reading a book for an hour
- Starting a new hobby

How to set goals

- Choose a goal that will give you enjoyment or achievement
- Be realistic about what you can achieve. An activity diary is a helpful way to record your current ability and help you set a baseline.
- Break a large/long-term goal down into attainable chunks.

For example, the goals about walking to the local shop could be broken down into targets like this:

Week 1: Walk halfway to the shops on alternate days of the week.

Week 2: If the baseline in Week 1 is met, either:

- sustain it for one more week, or
- consider walking another fifty yards towards the shops, on alternate days.

Write your goals down, display it somewhere obvious at home, tell your friends and family, get some support and encouragement, and reward yourself when you succeed!

Goals should be 'SMART':

Specific: is your goal too vague? If so, try to be clearer about it.

Measurable: how will you know if you have achieved your goal?

Achievable: how likely are you to be successful?

Rewarding: will you enjoy the results?

Time limited: when do you want to have achieved your goal?

Sleep hygiene

Many people with CFS/ME find they have difficulties with sleep. Poor sleep habits (often referred to as 'hygiene') can make these difficulties worse. Below are some essentials of good sleep hygiene.

1. Try to get into a regular bedtime regime. Go to bed when you are feeling sleepy rather than tired.
2. Put the light out immediately rather than reading or watching television in bed.
3. Set the alarm to wake up at the same time each day, and then actually get up at the same time each day, e.g. alarm goes off at 8am, and you get up at 9am each morning. Try not to vary this regime. It is important to get dressed each day, staying in your night clothes only reinforces the sick-role.
4. Avoid day-time naps or keep them to no more than 30 minutes.
5. Don't try to make yourself sleep, if you are unable to fall asleep after 20-30 minutes in bed, leave your bed and engage in a relaxing activity such as TV or relaxation tape. Don't go back to bed until you are sleepy.
6. Avoid heavy meals before bedtime or going to bed hungry (a small snack before bedtime may be helpful).
7. Reduce caffeine or nicotine consumption as much as possible. If you must have coffee, make it a morning drink only.
8. Avoid heavy alcohol consumption before bed.
9. Try to develop a sleep ritual before bedtime. This can be an activity you do every night before going to bed.
10. Eliminate non sleep activities in bed (such as TV, work or reading) to strengthen the association between bed and sleeping.
11. Ensure your room temperature is not too hot or too cold.
12. If pain is causing sleeplessness, you may need to speak to your GP or a member of the CFS/ME team for some pain management techniques.

Diet

What sort of diet should I be on if I have CFS/ME?

We normally suggest that people with CFS/ME try and make sure they have a healthy balanced diet. This means that you should be eating a variety of carbohydrate (bread, cereals, pasta, rice, potatoes); protein (meat, fish, milk, cheese, eggs, beans); fruit and vegetables.

What about sugary food?

Some people find it helpful to try and avoid too much sugary food during the day. This is because sugar can give you a burst of energy but this is followed by a low which can make functioning with CFS/ME even more difficult. If you need to put on weight we may suggest you have a sugary treat or snack at night as the energy slump will not affect you when you are asleep.

How often should I eat?

Many people find that five or six small meals are better than three big meals. This is especially helpful if you feel nauseated with food. It can also help with activity levels as the body then gets a constant supply of nutrients and sugar rather than bursts which make activity harder to regulate. It seems to help if you can have meals at a regular time as your body gets more used to food.

Are there foods I should eat more of?

There is some evidence that low iron stores are associated with fatigue. It is sensible to make sure that you eat a diet which has iron in it. Iron can be found in all meats, oily fish, shell fish, egg yolk, dried fruits, and fortified breakfast cereals. Iron absorption is increased by vitamin C. Vitamin C is also important to deal with the stress the body goes through with CFS/ME. Vitamin C can be found in fruits especially citrus fruits, berries, tomatoes, kiwis, dark green vegetables and potatoes. We would therefore recommend that you try and include these in your diet. We would not recommend you take vitamin supplements without discussing this with your doctor or dietician, as some of the supplements have side effects which may affect you if you have CFS/ME.

Are there foods that I should exclude from my diet?

There is no evidence that excluding a food will make individuals with CFS/ME better. Some people have found that excluding certain foods have helped. If you want to try and exclude a food we suggest that you do this with your doctor or a dietician as there are risks of causing more harm than benefit.

What should I do about drinks?

Some people find it helps their nausea if they drink frequent small amounts rather than occasional large volumes, especially at meal times. Remember to choose lower sugar drinks. Many people find both alcohol and caffeine make their CFS/ME worse. Caffeine is often in soft cola drinks and is also in hot chocolate (and in chocolate). You should avoid caffeine in the late afternoon and evening as this may make sleeping more difficult.

Understanding and managing stress

Stress within normal limits is a useful reaction to help us function in our daily lives. However, stress over a long time can be exhausting and affect our bodies, thoughts, feelings and behaviours.

Being unwell places us under stress. This, in turn, has effects on many aspects of our lives and places pressure on our immune systems, which in turn can make you feel more unwell.

When we are stressed, this takes up energy and we can then end up feeling even more tired.

Stress can be managed using various strategies.

First, let's look at how stress affects you.

Q. How does stress affect your...

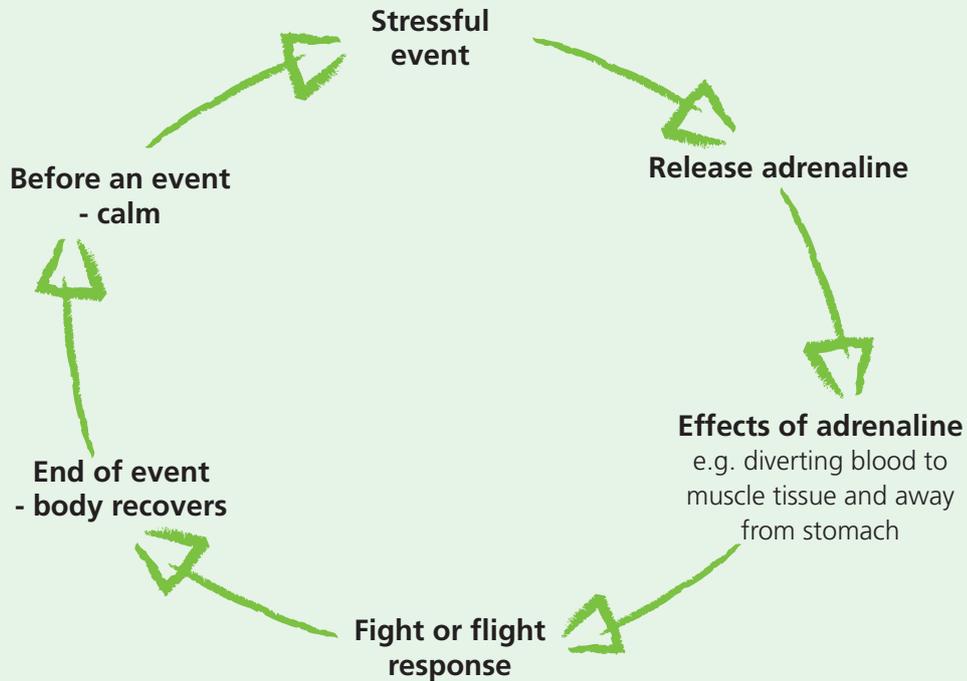
BODY	THOUGHTS	FEELINGS	BEHAVIOUR
Increased heart rate Rapid breathing Queasy stomach Sweating Muscle aches and pains	Catastrophising "I'm never going to improve" Forgetfulness Dislike of self	Frustrated Tired Fearful Irritable/angry Low mood	Argumentative Lack of concentration Avoidance Inflexibility Don't listen "Short fuse"

Now add your own examples below:

BODY	THOUGHTS	FEELINGS	BEHAVIOUR

Our body reacts to a stressful event by releasing a hormone called adrenaline. This process is known as the 'fight – or flight response', where the body prepares itself to fight or flee from dangerous situations. This is an instinctive response.

FIGHT OR FLIGHT CYCLE - a normal cycle that resolves itself



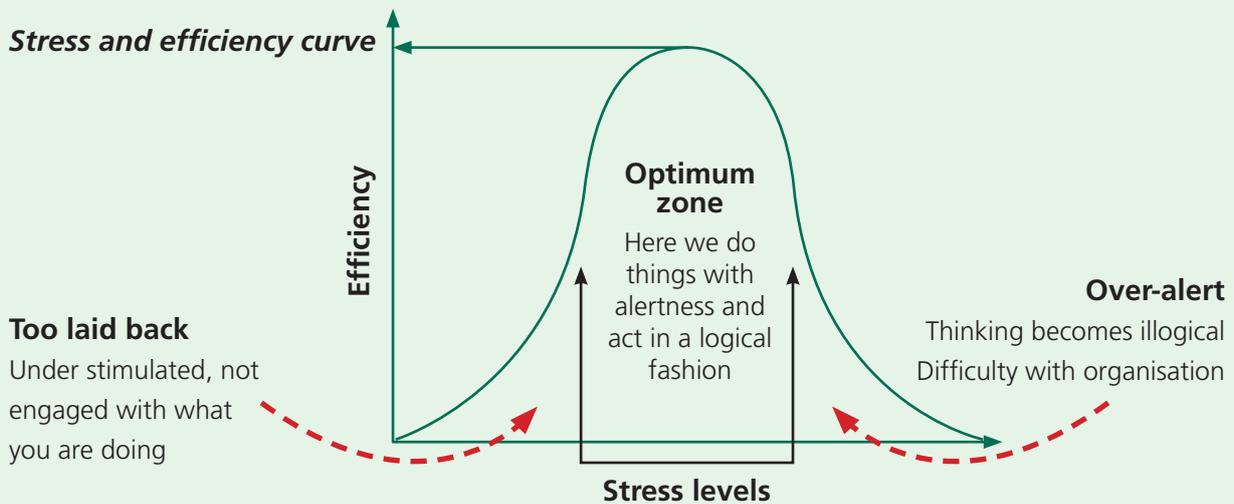
In contrast to the adaptive stress response shown above, an unhelpful stress response is one, which doesn't resolve – the stress spirals upwards and just doesn't seem to go away.

Stress is normal but needs to be managed!

It is important to recognise symptoms of stress - as the earlier you recognise them, the earlier you can deal with them, and the easier it is to manage the stressful situation.

Breathing techniques and strategies to control negative thoughts may help – they may not make the stressful events go away, but they can help to regulate the response.

Stress and efficiency curve

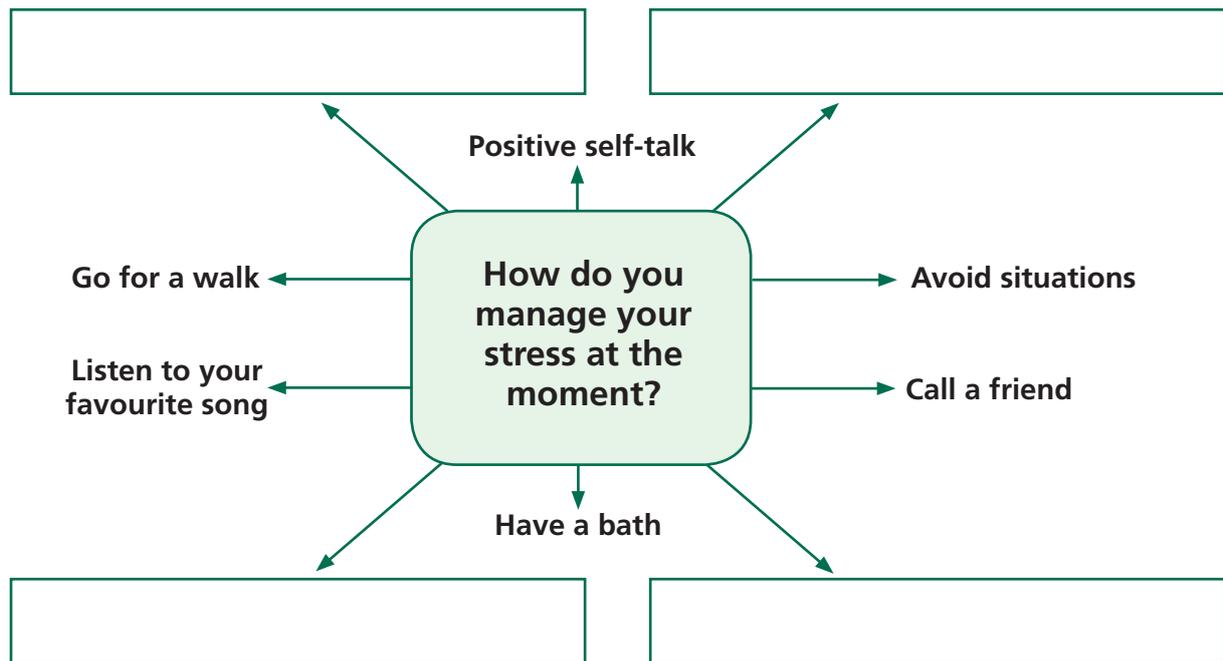


Stress management and relaxation pushes us into the Optimum Zone, which is where we are at our most efficient. Being over-stressed means that we are less likely to enjoy ourselves, to be less efficient in what we do and to think less clearly. Being over-stressed means we are wasting energy and we can become more fatigued.

Managing your stress will help to reduce some of your symptoms as well as boosting your immune system. Most people need to learn how to manage their own stress and the first step in this is recognising their own symptoms.

Q. So... how do you manage your stress at the moment...?

Add you own strategies in the boxes below:



When you do these things to manage your stress, ask yourself these questions:

- Q. How do these strategies work?**
- Q. Do they work in the long-term?**
- Q. If not, what else could you do?**

Space to add your own ideas:

Examples of stress management strategies

Behaviours

1. Time management
2. Assert yourself with others
3. Break larger jobs into achievable tasks
4. Goal setting
5. Communicate your needs, feelings and thought in a productive way

Resource ourselves

1. Get help
2. Check things out with others rather than avoid

Thoughts

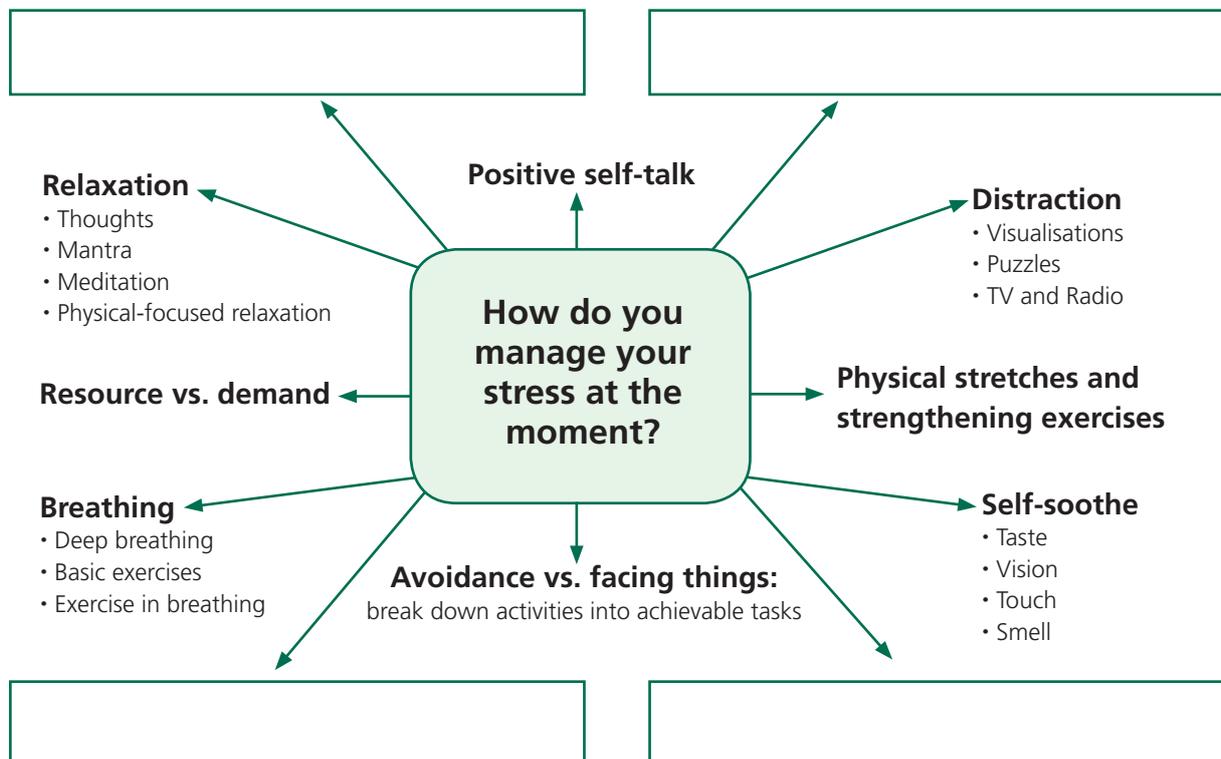
1. Challenge these ... are they based in reality?
2. Be optimistic ... positive self-talk
3. Distract from negative thoughts, e.g. watch TV, use relaxation techniques, and look at nature

Relaxation

1. Self-soothe – doing nice things for ourselves e.g. music, soft fabrics, good food, aromatherapy
2. Deep breathing
3. Stretches, light exercise
4. Experiment with different relaxation techniques – visual, physical relaxation etc

Q. So... what strategies can we use to help ourselves when we are feeling stressed?

Add you own strategies in the boxes below:



Relaxation:

The evidence surrounding relaxation and its benefits

The word 'relaxation' has several meanings, but for most people it means 'feeling good'. It can be used any time, anywhere, in any situation in order to restore a sense of self-control, even if only momentary. Its main purpose is to reduce negative physiological and emotional feelings through the release of tension, the restoring of energy and the encouragement of calming thought processes.

The benefits can be felt when relaxation is practised intermittently, but its greatest effect will be felt and maintained if practice becomes part of our everyday lives, an automatic process, triggered whenever we recognise aspects of our physical or emotional well-being that give us a feeling of not being in control. Relaxation is thus a way of counter-balancing our levels of stress, becoming second nature as with an athlete who trains or a typist who learns a keyboard.

The opposite state to relaxation is tension, often accompanied by anxiety. At some stage a whole range of physical, emotional and behavioural effects can be felt, as well as effects on logical thinking. For example: abnormal posture, neck ache, backache, headache, restlessness, nausea, tiredness, stiffness, sleeplessness, agitation, anxiety, and low self-esteem. One way for individuals to understand tension is to see it as a piece of elastic. When tense it is stretched tight, rigid, and inflexible; when loose it is firm but stretchable.

How then does relaxation help? Let us look at the evidence.

1. It acts as a safety valve, to release and relieve tension effectively.
2. It reduces our stress response to situations.
3. It relieves aching muscles.
4. It reduces pain, such as neck ache or backache, by releasing tension.
5. It reduces fatigue by helping us not to waste energy, enabling a quicker recovery after effort, as it recharges our internal 'batteries'.
6. It promotes sleep, by clearing the mind of everyday thoughts, and enhances our learning capabilities by clearing the mind of non-productive thoughts.
7. It can help to improve personal relationships because we can be calmer and more rational.
8. It gives one the feeling of well-being.
9. Where tension can increase the physical level of pain we are experiencing, relaxation actually reduces it.
10. If we are able to relax at will, tension will drop and be replaced by calmness, control, confidence and more energy to put to good use.
11. Relaxation gives us time for ourselves, to concentrate on our own well-being, shutting out everything else that is going on around us.
12. It provides an opportunity for us to regain control in a situation where our anxiety levels are high and we can begin to feel out of control.
13. It enhances our natural coping skills and acts as an enabling process for dealing with problems.
14. It can help increase our social skills: making friends is easier with someone who is relaxed and at ease.
15. It has a physiological effect on the body as the heart rate and breathing slow, releasing hormones into the blood stream, which enhances the feeling of calmness and reduces tension.
16. By voluntarily relaxing our muscles, we relax our minds too, so we can feel calmer emotionally as well as physically.

The aim of relaxation therefore, is to enable us to identify tension, by being aware of what it feels like:-

- By using techniques to alter its physical effect on us;
- To get rid of tension by relaxing individual muscles, the whole body and mind;
- To provide the ability to use a particular technique at any time or place, whenever we feel the need. This can be of short duration (a few seconds or minutes) or for a longer period of time (half an hour to an hour, or sometimes longer).

Relaxation: Simple relaxation exercise

For this short routine you will need to imagine a mental device to use during your relaxation. This can be:

- repeating a sound or word which you find relaxing, e.g. the word 'calm', or the sound of the sea;
- gazing on a fixed object in the room, e.g. a picture or ornament which you particularly like;
- thinking of an image which you find calming and soothing, e.g. a quiet country scene, a flower, etc.

The Procedure

This simple method involves focusing on your breathing and on a mental device.

1. Sit in a comfortable position. Close your eyes. Think about relaxing your muscles deeply, beginning at your feet and moving up to your face. Keep your muscles relaxed.
2. Breathe through your nose and become aware of your breathing. As you breathe out, focus on your own mental device. Breathe easily again and naturally.
3. Do not worry about whether you are good at this exercise. Keep a passive attitude and allow relaxation to happen at its own pace.
4. Distracting thoughts will probably come into your mind. Do not dwell on them; simply return to your mental device.
5. Continue for 10-20 minutes. When you finish, sit quietly with your eyes closed for a few moments and then with your eyes open. Do not stand up and begin moving around too soon. In time, the relaxation response will come with little effort and you will be able to respond to stress by relaxing, almost automatically. As always, regular practice is the key.

Positive and negative thinking

Q. Why is thinking important in CFS/ME?

In everyday life we are faced with many situations that can put us under stress. For example, failing to get a job, or having an argument with someone you love etc, are all situations that can feel stressful. Having Chronic Fatigue Syndrome/ME is also a source of stress.

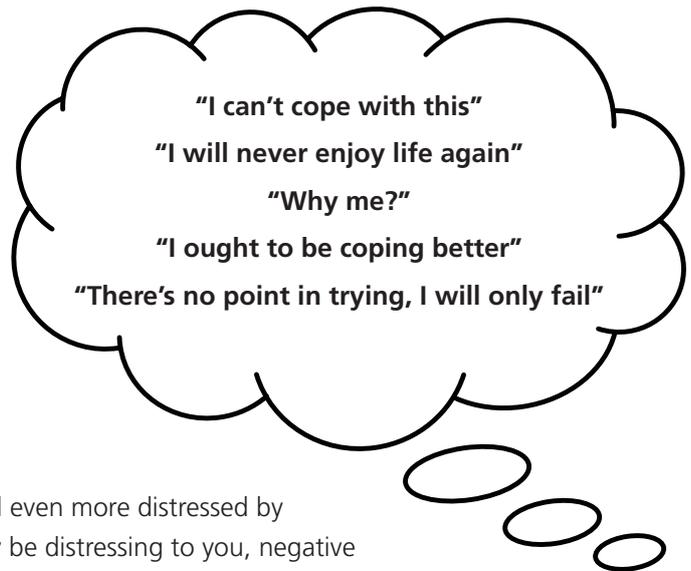
Stressful situations can produce a range of feelings. Some people report feeling depressed or unhappy, others may feel anxious, angry, disappointed or helpless. The way in which we respond to these events will affect how much we feel we are coping with the situation.

The way in which CFS/ME affects your emotions will partly depend on how you are thinking about it. It will also depend on what you are thinking about yourself, and your future. Here are some thoughts that people sometimes have:

The thoughts listed here are all examples of **NEGATIVE** thinking. These thoughts are not necessarily true, or easy to prove or answer. They are **UNHELPFUL**.

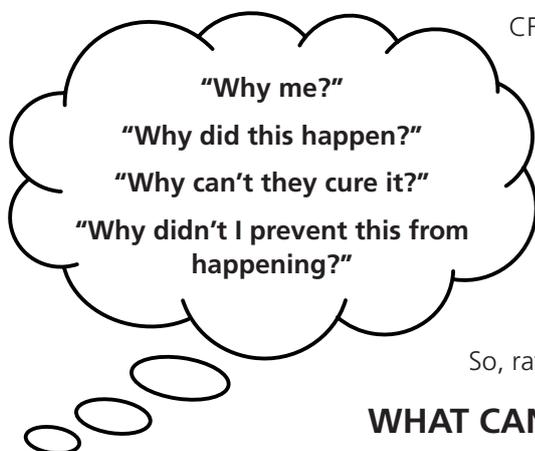
Negative or unhelpful thoughts can make you feel even more distressed by CFS/ME. At the end of the day, while CFS/ME may be distressing to you, negative thoughts will **ADD** to your distress.

Negative thinking does not only affect how we feel, but it also affects what we do. For instance, if you are saying to yourself "I can't cope", then it is likely you will feel less able to find ways of coping with CFS/ME. Negative thoughts therefore encourage negative feelings, which in turn stop you from using positive ideas for coping with fatigue.



Looking at negative thoughts about CFS/ME

The 'why' thoughts, eg:



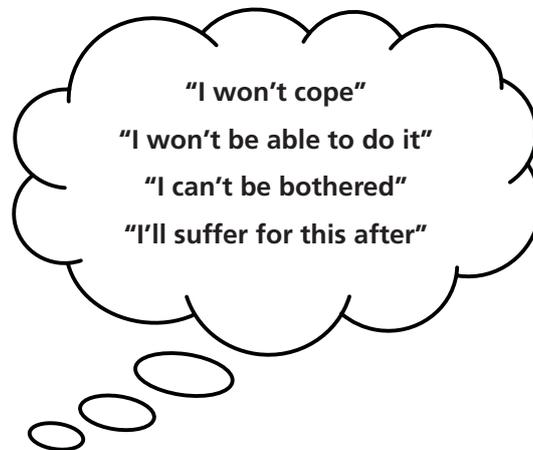
CFS/ME is complex and often there is not a simple explanation for why it continues. If you have had it for a long time, many attempts will have been made to answer this question. Continuing to ask yourself 'why' when there is no apparent answer will get in the way of you taking positive action to deal with your problem. You continue to focus on the past and on your fatigue, rather than looking for solutions or distractions.

So, rather than asking **WHY DID THIS HAPPEN?** ask yourself:

WHAT CAN I DO TO OVERCOME IT?

Looking at negative thoughts about yourself

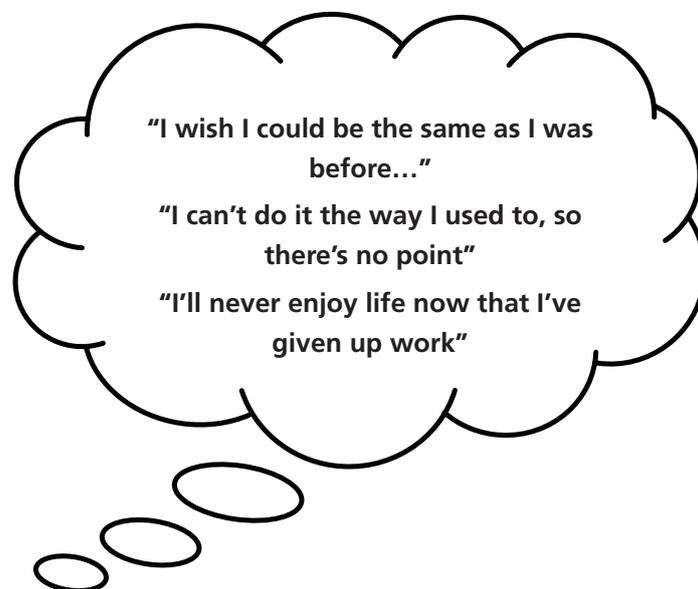
Having CFS/ME can sometimes eat away at your confidence in yourself. Perhaps you have found that you are sometimes prevented from finishing a task or going somewhere enjoyable. The next time the opportunity arises, how do you think and feel about it? Some negative thoughts in this situation are: -



These negative thoughts are not helpful in learning to cope with CFS/ME. If you often think along these lines then you will find yourself gradually avoiding more and more situations, becoming more inactive, feeling like a failure and focusing more on your CFS/ME.

Looking at negative thoughts about the future

Some people find it difficult to look to the future. Many people find themselves saying, "I'll never be the same as I used to be".



This is likely to be true. None of us, including non-CFS/ME sufferers, can ever re-trace the past. Wishing or hoping that this is not the case turns this fact into a negative thought.

These types of negative thoughts can result in us feeling depressed, demoralised and angry.

How to change negative thoughts

Negative thinking creates emotions and does not help us in dealing with CFS/ME effectively.

It is however possible to change the way in which we think about the situation, to replace negative thoughts with more positive ones.

1) Identifying negative thoughts

Patterns of thinking can become automatic over time. We probably don't notice much of what we are saying to ourselves. In order to change negative thoughts we have to start noticing them happening.

Carry a small notebook around with you for at least a week or so. Try to notice what you are saying to yourself in the course of the day and write these thoughts down. Notice particularly what is on your mind when you are feeling unhappy or upset. What thoughts are behind this?

2) Make your thoughts specific

What exactly do you mean when you say, "I can't cope"? What do you think is going to happen?

3) Challenge your negative thought

Ask yourself "How much do I believe this? What is the evidence that this will happen? Does it matter if it does? How can I prevent it?"

4) Find a more positive thought

Prove to yourself that your negative thought might not be true, and find a more positive way of thinking about the situation. Positive thoughts are thoughts that allow you to gain more confidence in yourself, and to take action that will make you feel more in control.

Examples of positive thoughts

"I may not be able to finish this, but I can do some of it today if I pace myself."

"If I use my relaxation tape, I will feel better able to cope."

"I can find a way of distracting myself from my problem."

However make sure that the positive thoughts you find are meaningful to you. If you do not believe these positive thoughts they will not help you.

Write down positive thoughts on a small card and carry them around with you. Get the card out and read them when you find yourself having negative thoughts.

5) Other strategies

- Do not avoid an activity because you feel you won't cope with it.
- Find new ways of carrying out an activity, through pacing.
- Keeping active can serve as a distraction from negative thoughts. Set yourself a plan of activities for the week ahead.
- Keep a diary of your progress week by week. Only write positive events in it e.g. do not compare yourself to how you were before, but to how you have been recently – look back over your diary.

There may be times when you feel disheartened or discouraged as progress may be slow. Those who appear to cope best with CFS/ME seem to be the people who try to go along with it, who adapt their daily life around their limitations and stop trying to fight it.

Coping with a chronic illness is hard as it impacts on every area of your life. However once you begin to accept CFS/ME and acknowledge there is no 'magic pill' or 'quick fix' and that recovery will take time, then you can begin to adapt your lifestyle using the evidence based strategies we have suggested.

Coping with setbacks

Most people with Chronic Fatigue Syndrome/ME will experience setbacks or flare-ups; times when symptoms worsen for a period of time. It can be difficult to maintain your levels of activity during these times. Different things will provoke setbacks, and they may last for varying lengths of time.

Each person will have different ways of dealing with a setback. The purpose of this self-help pack is to encourage you to become aware of those things that provoke a setback for you, and to develop a plan for coping with a setback when it happens. Do not blame yourself. Setbacks do happen; think of it as a problem to be solved.

What provokes a setback?

Setbacks don't always have clear-cut causes, but there are a number of things which can contribute to one:

Overdoing it - This may be the result of taking on too much, or simply as a result of doing one activity for too long. Setbacks can be triggered if you fail to pace yourself properly, or if you fail to plan, prepare and prioritise.

Stress - A period of stress in your life may provoke a setback. Be aware of those things that upset you and spot the signs that you are becoming unduly stressed. Stress management may be especially helpful at these times.

Periods of illness - Following a bout of illness, you may be more prone to a setback. Remember to restart activities and exercise gradually by pacing yourself.

Low mood/seasonal factors - many people find that there is an interaction between their frame of mind and their energy levels.

Not all these factors apply to everyone. It is worth recognising as many signs and characteristics from your own experience of setbacks to help you next time. Use the space below to list those warning signs which you have noticed before, and add any new ones as you become aware of them.

Warning signs:

Even with the best of planning, it may be impossible to avoid a setback. However, if you do have one, could you use it as way to learn? Did you ignore the signs? What could you have done differently?





Useful contacts

Greater Manchester CFS/ME Helpline: 0845 123 2390

National support Groups:

Action for ME

www.afme.org.uk

Tel: 0845 123 2380

Tel: 01179 279 551

Association of Young People with ME

www.ayme.org.uk

Tel: 08451 23 23 89

Local Support Groups:

Stockport ME Group

Tel: 0161 432 0390

(10 am - 4 pm, Monday to Friday)

www.sme.subn.co.uk

Bury and Bolton ME Group

Pam Turner - Tel: 01204 793846

www.mesupportgroup.co.uk

This document was produced for the Lincolnshire CFS/ME service by the Lincolnshire Partnership NHS Trust. It has been adapted, with permission, for local use within Greater Manchester.

This leaflet can be produced in other languages on request.
We can also provide the information in other formats such as Braille and audio CD.