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

Self Help Information for Patients

‘To equip people affected by CFS / ME with the skills for self-management towards a better quality of life’.

Adult CFS / ME Service

February 2017
Review February 2019
What this self-help booklet aims to do

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

We hope that this booklet will give you some basic practical guidance on how to manage your CFS / ME effectively.

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Acronyms:
NICE – National Institute of Clinical Excellence
CFS – Chronic Fatigue Syndrome
ME – Myalgic Encephalomyelitis
CBT – Cognitive Behaviour Therapy
GET – Graded exercise therapy
Introduction

The CFS / ME service consists of a team of health care professionals covering the whole of Cambridgeshire. The team includes a Specialist Nurse Practitioner, and three Occupational Therapists.

CFS/ME is a complex condition and there is, as yet, no consensus on a single cause.

However there are things that help you manage this condition. These include early diagnosis and symptom management.

There is also evidence that all of the following can support improvement:

- A balanced approach to rest and activity.
- Improving sleep patterns.
- Gradual reintroduction of exercise (very minimal at first).
- Addressing unhelpful attitudes, such as perfectionism if they are part of the problem.
- Improving stress management.
- Reasonable adjustments at work or in education.
- Setting manageable goals to move forward.

We will support you and your GP with a self-management strategy / plan to manage your condition in a way appropriate to you. Please visit our website for further information:

www.cpft.nhs.uk/services/chronic-fatigue-syndrome-and-myalgic-encephalomyelitis.htm

As we wish to improve the service we would appreciate your comments.

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

Adult CFS / ME Service
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Sugar Way
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Peterborough PE2 9QB

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Cpm-tr.cfsme@nhs.net

If you would like any further information about the CFS / ME Service, please contact us using the details above.
What is Chronic Fatigue Syndrome / ME?

Many people experience Chronic (long-term) fatigue and this is not necessarily CFS / ME.

Although one of the main symptoms of Chronic Fatigue Syndrome / ME is severe and prolonged mental and physical fatigue, alongside this there is a range of other symptoms which can include:

- Headaches
- Widespread muscular and / or joint pain
- Sleep disturbance
- Unrefreshing sleep
- Difficulties with concentration and memory (“brain fog”)
- “Post exertional malaise” – feeling fatigued and ill after activities
- Sore throats and tender glands
- Dizziness and balance problems
- Odd sensations like pins and 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 others.

What causes CFS / ME?

We often see people who have developed CFS / ME following an infection, such as glandular fever. Other people can identify a period of stress leading up to the start of the illness. A combination of infection and stress is also common. 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. However, this picture is far from complete at present.

How is CFS / ME treated?

We can help to reduce some of the symptoms by advising your GP regarding evidence based medication and therapeutic approaches as per the NICE guidelines, but some people face the challenge of living with these ongoing symptoms for some time.

There is good news in that we know that these symptoms can gradually improve in many people. We also know that learning ways to manage the condition can help people to make improvements.

Our service aims to help patients and their doctors identify the condition, and then offer support and management strategies to manage the condition effectively and increase the likelihood of recovery.
Understanding CFS / ME: The Biopsychosocial Model

‘Biopsychosocial’ is a term we use to understand the various factors that affect people with CFS / ME. Using this term does not mean we believe your illness is psychological, as many health conditions influence us in all three areas. As you will have experienced, CFS/ ME causes many different symptoms and influences many different parts of your life.

For example when you have CFS / ME you are:

- Physically unwell and have several **biological** symptoms – fatigue and pain.
- You may feel less like your normal self and this can lead to feelings of unhappiness, frustration, confusion, anger etc. – **psychological**.
- You may not feel able to see friends as much – **social**.

Whatever is happening to your body physically (e.g. fatigue, pain, dizziness) is also having a knock on effect **psychologically** (changes in the way you feel and behave) and **socially** (changes in activity, working life, and seeing friends). It is important to understand how CFS / ME affects these aspects of your life (not just the physical symptoms) in order to help you improve the quality of your life.

An example of CFS / ME:

_A hard working 30 year old woman is doing well, working hard, exercising and socialising. She gets a viral infection around the time she is promoted and feels under pressure to take only one day off before returning to work. She is working hard and more so because she is not 100% healthy. She is able to ‘push on’ by stopping her regular exercise and social outings so she can rest and sleep more when not at work. She starts losing health and fitness even becomes physically more vulnerable, feels miserable and her work is even harder – we call this a boom and bust cycle ……_

1. **Precipitating (triggering) factors**

There are many possible precipitating factors that may ‘set off’ CFS / ME, such as a viral illness or accident, an accumulation of stress, a sudden unexpected loss or accident. It is unlikely there will be just one trigger to your CFS / ME, although this is possible. Many triggers may come together at the same time, overloading the body physically and mentally. These triggers may have accumulated over time or be sudden and overwhelming.

**What factors may have triggered your CFS?**

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2. **Perpetuating (maintaining) factors**

Those factors that caused CFS / ME at the beginning are not always the same as those that are causing your symptoms to continue. Being aware of things that make symptoms worse right now is very important. This may include ‘overdoing’ it, arguments, poor sleep, low mood, cold weather, other health conditions etc.

Of course, there may also be things that you find help your symptoms, such as recognising external and internal strengths, i.e. family support, ability to practice relaxation.

*What maintains your CFS / ME or makes your symptoms worse? What helps improve you?*

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<th>SOCIAL</th>
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3. **Predisposing (pre-existing) factors**

Finally, sometimes we can recognise pre-existing problems that may have increased your risk of developing CFS / ME. This may include lifestyle that allowed you very little time to rest or relax, a biological vulnerability to illness, difficulty saying ‘no’ to requests, extremely high expectations or ‘perfectionist’ or a prolonged exposure to stress and trauma.

**Predisposing** factors do not *cause* your CFS / ME but make it more likely that CFS / ME will be triggered. Of course not all predisposing factors affect everyone, but it is worth looking at them in case they do add something to your understanding of your current problems.

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Managing CFS / ME

Approaches recommended by the NICE guidelines for CFS / ME include Activity Management, GET, and CBT, all related to the individuals current level of functioning. This booklet contains brief information about each.

Activity Management

One of the most important skills you will need to learn, to help you with your recovery and reduce your symptoms of CFS / ME will be activity management which will include GET.

Activity management will encourage you to look at how you carry out activities and the amount of energy you use. It is important you recognise which activities are most demanding on your energy. This will vary from person to person. Learning how much you can do before the onset or worsening of fatigue and other symptoms can take time and often trial and error.

Activity management is a way that can help all of us balance our daily activity between doing things and resting. 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 reduce activity when they feel unwell. This can lead to swings in activity and if you have CFS / ME you may find that you over do things on one day and then need several days to recover. This is often referred to as boom and bust (see below). It is hard to improve while you are in this pattern.

The team will help you to understand your current activity patterns. Initially you will be asked to complete an activity diary which records the type of activity you do, your energy levels and any fluctuations in your energy levels during the day. It will be an important initial tool in helping you to make the changes necessary and establish a level of activity that you can sustain, without making your
symptoms significantly worse. This level of activity is often referred to as your baseline. You will know this approach is helping, once you start to feel more in control.

Once you have achieved your baseline, you will be able to introduce gradual increases in activity. It can be helpful to visualise these increases as a series of small steps. We would recommend each step is an increase in activity of approx. 10% - 20%. Each step or increase then needs to be sustained over a period of 2-3 weeks before a further increase or step is taken. It is usually best to increase only one or two activities at a time for example extending reading time by a few minutes and adding one minute to a daily walk. Trying to increase activity in every area of your life simultaneously could be challenging.

Balancing different types of activity is also important. Types of activity can be referred to as “Physical” involving mainly movement, and “Cognitive” involving concentration, memory and mental processing.

Examples of physical activity would be:

- Getting dressed
- Taking a walk
- Making a meal
Examples of cognitive activity:

- Watching TV
- Using a computer
- Phone calls
- Having a conversation

Balancing means not doing any type of activity for too long – the length of time will vary according to your symptoms. It may be helpful to break up tasks into manageable chunks and take breaks in between.

Good quality rest and relaxation is an essential part of your activity management. There are several techniques or skills you can learn to help you relax, which will be discussed later.

The activities you are gradually increasing should be across a wide range of areas including enjoyable activities / interests, personal care, housework, family commitments and employment or community activities. It is not all about exercise however we do encourage people to start including a little exercise in their daily activities.

**Graded Exercise Therapy (GET)**

GET involves a structured activity management programme that aims for a gradual increase in activities (including aerobic exercise at the right point of recovery).

It is tailored to your current capacity and takes into account that both physical and cognitive functioning are usually affected by CFS / ME and both need to be built up gradually. Alternating increasing activity with adequate rest periods is key - sometimes introducing several short rests per day is the first step before trying to increase activity at all (particularly where patients are working and / or have young children).

**Key Principles are:**

- Find a stable baseline of activity / exercise that can be managed six days per week and not just something that can be achieved on a ‘good day’.

- Expect increasing activity to cause minor increase in symptoms, but slow progress if symptoms are severe or prolonged.

- Increase gradually – in 10% - 20% increments after an activity has been successfully maintained most days for a period of around 2 weeks. I.e. increasing a 10 minute walk to 11 minutes initially for example, so increments are small, steady and sustainable.
Gym visits and exercise classes are usually counterproductive until you can manage 30 minutes of gentle exercise routinely without a severe increase in symptoms. Rapid or irregular increase in exercise is usually unhelpful. The frequency of exercise is important before considering the intensity of the exercise.

**Stages of Therapy**

We aim to work alongside you in moving through the three stages of the therapy program supporting you to gain control and improve your quality of life.

In outline these stages are:

- **Stabilisation**
  - Understanding and acceptance.
  - Reducing ‘boom and bust’.
  - Introducing regular relaxation.
  - Improving sleep, reducing symptoms.

- **Increasing Tolerance**
  - Gradual increase in activities.
  - Introduction of / increase in exercise (GET)
  - Looking at difficult thoughts and feelings
  - Managing demands of others.

- **Maintenance**
  - Wellness plan / progress summary.
  - Plans for sustainable increases in activities, exercise, work, and / or education.
  - Coping with setbacks
  - Future goals
  - Things you wish to still work on.

This process will be different for everyone as people start at varied levels, and people’s life circumstances are very diverse.
Setting Goals

Q. What are goals?

Goals are clear statements of your planned steps to move forward and will obviously vary from person to person depending on the level of illness.

Some examples:

- Walking to the local shop (10 minutes every day)
- Managing to vacuum a room
- Meeting a friend for a coffee once a week
- Reading a book for an hour
- Doing a craft activity for 30 minutes per day
- Reading for 10 minutes each day
- Reducing daytime sleep to one hour
- Two stretch exercises once a day

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 to attainable chunks.

For example, with a goal of meeting a friend for a coffee initially this could be at home for 30 minutes and then the time could be extended over several weeks before moving to meeting elsewhere.

Write your goals down, and display them somewhere obvious at home and get some support from friends and family.

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 goals?

Achievable: how likely are you to be successful?

Realistic: are you considering the challenges involved?

Timed: when will you review your progress?
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.

The most important point to remember when trying to get to sleep is not to try too hard. Worrying about sleep is much more tiring than just being awake.

Before bed:

• Establish a regular routine each night. This helps to ‘cue’ you to sleep.

• Eating and drinking for the last few hours before bed is likely to stimulate your body so try to do these things earlier in the evening.

• Read or watch television outside the bedroom, the bedroom should be associated with sleep and perhaps sex.

• Try not to watch scary movies, these increase your adrenaline and stimulate wakefulness. Comedies are good as endorphins will be released which can help you to relax.

• Set your alarm each night and aim to get up at the same time each morning irrespective of how much sleep you had during the night.

• Taking a warm bath and/or having a massage are good for inducing sleep.

• Avoid vigorous exercise prior to bed. Yoga and stretching are good non-aerobic forms of exercise.

Once in bed:

• Try to turn your mind away from the days’ activities, any worries you may have or what you will do in the future. This is not the best time to think of these things. Think about pleasant places or events or use your imagination to conjure up relaxing images.

• If you find that you are unable to sleep whilst in bed, perform your relaxation routine as good relaxation can be as restful as good sleep.

• If you cannot get to sleep, GET UP after 20 minutes and go and do something boring and relaxing to allow your body to feel sleepy again. Have some boring books or videos on hand.

• The environment in which you sleep is important. Try and ensure your bedroom is quiet, well-ventilated, dark and a comfortable temperature.
• Even if you did not sleep well, try and get up at the usual time. If your sleep hours vary too much it will become harder to get to sleep the next night. This is very similar to the effects of jet-lag.

**Avoid day time naps or keep them to no more than 30 minutes before 3pm. If you are sleeping excessively in the day you may need to reduce your sleeping hours gradually. It will be too difficult to cut down by several hours immediately. Your Occupational Therapist will be able to support you with this.

**Diet and Supplements**

There is a lot of conflicting information around regarding the role of diet and supplementation in CFS / ME.

The key thing is to be eating a healthy balanced diet and to be eating regularly. This can be difficult because of the amount of energy required to buy, prepare and eat food. Having healthy food that can be stored and that requires minimal preparation available is helpful at least as a backup. (For example a quick to prepare porridge or peanut butter and crisp bread - but obviously something that appeals to you!).

There is some evidence that Low GI (Glycaemic Index) foods which release energy slowly can improve energy levels a little. High sugar and high caffeine foods and drinks are best avoided as far as possible as they can give a short term boost in energy followed by a drop.

Special diets that exclude particular types of foods are not generally recommended for people with CFS/ME although some people with irritable bowel symptoms can find reducing dairy or wheat intake helpful but it would be advisable to discuss with a dietician if possible.

If you have nausea snacking on starchy foods, eating little and often, and sipping drinks slowly can help. If this doesn’t work, and your symptoms are particularly severe, you may be offered drugs to control the nausea.

There is not enough evidence on using supplements such as vitamin B12, vitamin C, Co-enzyme Q10, magnesium, NADH (Nicotinamide Adenine Dinucleotide) or multivitamins and minerals for these to be formally recommended as a treatment for CFS/ME. However some people decide they do want to take these supplements and this is unlikely to cause any problems as long as you stay within the safe limits recommended by the Food Standards Agency. There is more information on the FSA website (www.eatwell.gov.uk).
Understanding and managing Stress

We are not suggesting here that stress directly causes CFS / ME. However it seems that for many people it is one of a number of factors that makes them vulnerable to physical illnesses and makes recovery more difficult. There is evidence that long-term stress, which causes over-production of cortisol, can compromise immune functioning. This may explain a link between CFS/ME and stress for some people.

Stress is a normal reaction to the challenges we face in life. A certain amount of stress is necessary to keep us all going; without it, we would feel bored and listless. However, continued stress over a long period of exhausting, and if your energy levels are low due to CFS, energy because of stress is a particular problem.

People differ both in the way that they react to stress and the extent to which they are aware of their own stress levels. Below are some of the possible effects that stress may have; it may affect us physically, emotionally and in the way that we behave.

<table>
<thead>
<tr>
<th>Physical Changes</th>
<th>Emotional Effects</th>
<th>Other people Notice</th>
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<tbody>
<tr>
<td>Heart racing</td>
<td>Tense</td>
<td>“Short fuse”</td>
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<tr>
<td>Sweating</td>
<td>Frustrated</td>
<td>Always rushing</td>
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<tr>
<td>Breathing faster</td>
<td>Afraid</td>
<td>Loss of humour</td>
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<tr>
<td>Queasy stomach</td>
<td>Irritable / angry</td>
<td>Impatience</td>
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<tr>
<td>Trembling</td>
<td>Tiredness</td>
<td>Don’t listen</td>
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<tr>
<td>Dry throat</td>
<td>Fear or dread</td>
<td>Sudden mood change</td>
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<tr>
<td>Muscle tension</td>
<td>Argumentative</td>
<td>Forgetful</td>
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Other Effects

- Poor concentration
- Memory problems
- Difficulties making decisions

All of the physical reactions above are normal. When we face physically threatening situations these responses help the body prepare itself for action. This is known as the ‘Fight or Flight’ response because the body prepares itself to fight, or run away from dangerous situations. This is a helpful, instinctive response. When the dangerous situation is over, the body can begin to recover.

In modern society, a lot of the things that create stress are not dangerous situations where we can physically fight or run away from something. For example, financial worries or family problems can make us feel under stress. In these situations stress levels may rise and remain quite high, and after a while we may begin to feel the effects of this. Over a long period of time stress can contribute to making us feel exhausted and unwell.
Chronic Fatigue Syndrome / ME and Stress

Long term illness can cause its own worries. Worrying can trigger the stress response, and muscles then become tense. Changes in muscle tension can be quite subtle, and it is difficult to be aware of it happening. This increased tension can worsen fatigue, and aggravate any pain, leading to more stress and worry in a cynical manner.

We also tend to put ourselves under stress by doing some of the following things:

- Taking on more than we can possibly do.
- Never saying ‘No’ to people.
- Never being satisfied with what we have achieved.
- Not relaxing enough.

Being aware of some of these things can be useful. There are positive management strategies for stress, and for the symptoms of stress.

Reducing stress through relaxation

Most people already have things they tend to do when they feel quite stressed – there are lots of possible ways of tackling it. For example, some people listen to music, talk with a friend, or go for a walk. Regular exercise can also help to reduce tension in the muscles, and give a feeling of wellbeing. Sometimes your usual methods of handling stress may become less effective when stress rises beyond a certain point. It is useful during these times to have some specific methods of dealing with stress. They may also have become difficult to do because of your illness.

Becoming aware of the signs of increased tension and stress and spotting them at an early stage is a useful start. We are often not aware of tension in our bodies. Listening to a relaxation track is one way of beginning to become more aware. Learning to relax means that you can reduce muscle tension and break out of the vicious cycle of fatigue, stress and tension, which can be worsened when living with CFS / ME.

Relaxation is different from watching TV or reading a book, where it is quite easy to remain tense, and may be tiring in their own right. When practising relaxation you need to find somewhere quiet and warm, where you can find a comfortable position and you will not be interrupted.

At the beginning relaxation may be frustrating if you find it difficult to concentrate or feel it is not working. It is a skill, and is likely to take a bit of practice to master. Remember that there are different forms of relaxation, to meet individual preferences. It is worth seeing the initial stages as an investment of time, which can pay dividends in the medium and long term. Daily practice will give the best results.
Q. So... how do you manage stress at the moment...?

Add your own strategies to the star below:

- Watch the TV
- Go for a walk
- Avoid situations
- Listen to your favourite song
- Call a friend
- Have a cigarette

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

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Examples of stress management strategies

**Behaviours**

- Time management
- Assert yourself with others
- Break larger jobs into achievable tasks
- Goal setting
- Communicate your needs, feelings and thoughts in a productive way

**Resource Ourselves**

- * Accept Help

**Relaxation**

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

**Thoughts**

- * Challenge these, are they based in reality?
- * Be optimistic, positive self talk
- * Distract from negative thoughts, e.g. watch TV, use relaxation techniques

**Cognitive behaviour therapy**

**Think better to feel better**

An approach based on Cognitive Behavioural Therapy (CBT) can be useful for CFS / ME. This involves looking at the way thoughts, feelings, behaviour and physical sensations are interlinked.

This DOES NOT imply that CFS / ME is not real, just that, as for many physical conditions, there is evidence that the way we think about illness and how we manage it makes a difference.
Humans are very complex beings. So how we think will affect how we feel and what we do, equally what we do influences how we feel and what we think. Our thoughts, feelings and actions are always interlinked.

CBT for CFS / ME overlaps very much with what we discussed earlier regarding the Biopsychosocial approach. It involves identifying and working on anything that may be maintaining the illness and
making it harder to recover. This will usually include lifestyle factors such as “no time to rest”, “boom and bust activity pattern” and poor sleep but for some people may include thoughts such as “my house has to be perfect”, “I always have to put other people first”, “I can’t say no to my kids”. CBT can also help people to look at and challenge these thoughts if they want to.

Most people have a good balance between positive and negative thoughts.

When we become unwell it is easy for our thoughts to become more negative and this can make us feel more frustrated, angry and sad. Negative thoughts can become automatic the more we pay attention to them, they seem to pop up by themselves and can be difficult to get rid of. The first thing to remember is that our thoughts are not facts. So identifying Automatic Negative Thoughts (ANTS) is a good place to start.

Here are some examples:

“*I woke feeling exhausted, I must be getting worse*”

“*There’s no point in trying, I’ll only fail*”

“*I’ll never get any better*”

“*I am useless; I didn’t achieve everything I’d planned to do*”
Noticing these thoughts is the first step – many people find it helpful to jot them down.

The next step is to think about whether they are really true and if not to try to come up with a more balanced alternative. Here are some examples of negative thought patterns and some more balanced or helpful alternatives.

When you have a negative thought, ask yourself these questions.

They may help you to think of a more helpful thought.

Q: Am I forgetting the good things?

There’s so much to do, I’m not getting anywhere, and it’s not working!

But what about all the things I have done? I must not forget them. They still count. Small steps ..I have made some progress.

Q: Am I reading other people’s minds?

Everyone is fed up with me.

How do I know that? They haven’t said they are fed up with me. They may just be too busy to talk to me at the moment. They may have other things on their mind, or maybe they are feeling fed up for some other reason.

Q: Am I thinking the worst?

I feel so ill. I know I will have a relapse and be worse than better.

I’m thinking of the worst possible outcome! It doesn’t have to end in disaster! I may not get worse. If I do it might not be that bad, or I might even feel better.
Q: Am I labelling myself, (or others)?

I can’t help with the housework because I’m so tired. I’m just useless!

I might not be able to do much housework right now, but that doesn’t mean that I always have been and always will be ‘useless’ in every situation. In fact there are ways that I can be helpful, even if I can’t do very much physically. Not everyone is perfect all the time.

If you are seeing a therapist within the CFS / ME Team they will be happy to help you identify and challenge unhelpful thoughts.

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 become 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 can help you next time. Use the space overleaf 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 a way to learn? Did you ignore the signs? What could you have done differently?

Setback Management

An important part of learning to manage your CFS / ME is learning to manage setbacks as best you can. This means that you will be able to recover more quickly and feel more confident in the way you handle a setback. Here are some reminders of useful strategies that may help.

**Relaxation:** Remember the importance of proper, recuperating relaxation. Try to use your favourite relaxation technique.

**Planned Rest:** What have you found out about the most effective use of rest? It is planned, time limited and enjoyable.

**Activity:** It’s tempting to stop completely when you are fatigued – don’t – remember what you have learnt, and adjust your baseline accordingly.

**Prioritise:** Put your energy into the most important areas of your life first. Try and keep some energy each day to do activities you enjoy.

**Compromise:** Are you asking too much of yourself at present? Don’t be afraid to step back and reconsider your expectations during a setback. Remember to recognise what you are achieving.

**Socialise:** If you’re very tired it is easy to feel like isolating yourself. Remember that being in touch with someone can be helpful, so what about giving someone a ring, or inviting a friend round?

**Pamper:** If the going is tough, pace yourself and give yourself a break. If a massage or relaxing shower or bath helps, why not? Decide how you will indulge yourself as a kind of compensation next time a setback occurs.
Thinking: Remember the way we think influences how we feel. In the midst of a setback it is easy to slip into bad habits and dwell on the negatives. Try to be aware of this and try out different ways of thinking.

Not all these strategies will apply to you and you may have developed some additional ideas for successfully managing or reducing the length of a setback. Use the space below to write down ideas that you have for managing your own setback and add any new ones that may help.

Setback Plan:


Service Details

- Open Monday to Friday – 01733 774583, answer machine available and responded to as soon as possible
- Service email address: cpm-tr.cfsme@nhs.net
- Website address: www.cptf.nhs.uk/services/chronic-fatigue-syndrome-and-myalgic-encephalomyelitis.htm

Current Clinical Staff

- Alison Jack – Nurse Specialist
- Gill Watkins – Specialist Occupational Therapist
- Nicky Patterson – Specialist Occupational Therapist
- Natalie Gadsby – Specialist Occupational Therapist