Chronic Fatigue Syndrome (CFS)/Myalgic Encephalopathy (ME) Management Programme

Clinical Psychology
Clinical Sciences Building
0161 206 5588
CFS/ME Management Programme

The Chronic Fatigue Syndrome (CFS) / Myalgic Encephalopathy (ME) management programme is a 6 week group intervention designed to help you manage your condition.

Research has shown that learning new ways to manage your energy and other resources can enhance your lifestyle, increase self-awareness, and substantially improve your health. Coming to the group may also decrease your feelings of isolation and help you to improve your support network. We cannot provide you with a cure but, given patience, determination, and courage on your part, we can help you to achieve a gradual recovery or at least a partial return to previous activity levels.

If you require a referral to the service please discuss this with your Consultant or GP.

PLEASE NOTE: This workbook is suitable to show to family, friends, employers, colleagues, carers or other health professionals. However, if sharing with other CFS/ME sufferers please advise it does not replace a referral to a recognised CFS/ME service.
What is CFS/ME?
Introduction to pacing
CFS/ME Management Programme Aims

Better (self) management of condition

- Improved lifestyle
- Learn new ways to regulate energy and other resources
- Increased self-awareness
- Decreased isolation
- Enhanced support network

Gradual improvement in levels of functioning!
Introduction to CFS/ME self management

The information in this workbook has been put together to help you understand what CFS/ME is, how it affects you and to help you identify what management strategies work best for you.

What is CFS/ME?

Myalgic Encephalomyelitis (ME), Post Viral Fatigue Syndrome (PVFS), and Chronic Fatigue Syndrome (CFS) are names that have been used to describe a syndrome, which currently is thought to be a similar condition. There has been much debate and we are still developing our understanding of this condition. Currently the preferred term is CFS/ME and this will be used throughout this leaflet.

CFS/ME can affect people in many different ways and people will experience different symptoms. The main symptom which affects all sufferers is persistent fatigue. This is different from the normal tiredness people feel when well as it does not normally go away after resting.

The fatigue is usually severe and disabling, affecting both physical and mental functioning.

Other common symptoms in CFS/ME include:

- Muscle/joint problems
- Sore throat
- Headache
- Dizziness
- Sweating
- Poor concentration
- Memory difficulties
- Sensitivity to light
- Twitching muscles
- Drowsiness
- Post-Exertion Exhaustion
- Nausea
- Sleep problems.

What causes Chronic Fatigue Syndrome?

CFS/ME is a complex illness. Currently research has shown there can be a range of factors that cause an individual to develop CFS/ME. Theories about the cause of CFS/ME suggest that it may be a result of a combination of physical and psychological factors. Genetics may also play a role (you are more likely to develop it if you have a family history of CFS/ME).

Some predisposing factors including stress, lifestyle, personality (e.g. high achievers) may make it more likely someone will develop CFS/ME when coupled with a trigger such as a virus, a traumatic event, surgery or a vaccination. Factors such as stress, poor sleep, overexertion and deconditioning can then work to maintain the symptoms of CFS/ME. While we cannot change the predisposing and triggering factors we can work towards reducing the factors that maintain the symptoms or make it worse.
How do activity and rest interact in CFS/ME?

For most people after resting they feel refreshed with energy. Normally, rest will allow full recovery and our “batteries” to be fully recharged. However this doesn’t seem to be the case in people with CFS/ME. Regardless of the amount of rest they take this never fully recharges their batteries; it only provides a small recovery of energy and limited short-term symptom relief. In the long term prolonged periods of rest may be unhelpful, as it reduces exercise tolerance and can produce increased sensitivity to activity. This means that increased symptoms of pain and fatigue will occur at progressively lower levels of activity.

Prolonged rest therefore brings about short term symptom reduction but a longer term increase in disability.

Boom and bust

Due to the persistent fatigue, when sufferers do have some energy it can be easy to slip into the habit of trying to make the most of it and do as much as possible. We call this the BOOM and BUST cycle. On the days when you have energy you have a BOOM of activity, but because this uses up all your energy the next couple of days are needed for recovery; you are BUST. This can become a vicious cycle that can maintain your CFS/ME.

Predisposing factors (e.g.)
• Stress
• Genetics
• Prolonged high achievement/standards

Triggers (e.g.)
• Virus
• Surgery
• Trauma
• Stressful event
• Vaccination

CFS/ME Symptoms

Maintaining factors (e.g.)
• Deconditioning
• Disorganisation
• Over-exertion
• Stress
• Denial
• Poor sleep

You cannot undo these....

These you CAN do something about!
Rest and CFS/ME

People with CFS/ME often find they are resting in a way that is unhelpful for them:

1. The amount of rest may vary: on bad days you rest more and on good days less. Rest is therefore fatigue and symptom dependent rather than being consistent. This means that your body never has the chance to get used to a regular routine.

2. Rest may not be really relaxing: even if you are not doing much you may still feel tense and worried, which means that it will not feel refreshing.

3. Although you probably feel that you need more rest, there is a point where too much rest becomes counterproductive. Excessive rest can make you feel even more tired, is de-motivating, impairs the quality of your sleep, reduces physical fitness, weakens the heart, reduces muscle strength and increases muscle fatigue.

In addition your activity level probably tends to fluctuate (see the ‘Boom/Bust’ diagram above). The key to breaking this pattern is to plan a systematic programme of scheduled rest and activity.
Week 1

What is CFS/ME? Introduction to pacing

Scheduling Rest and Activity

The aim of cognitive-behaviour and graded activity therapy is not simply to be more active, but to make activity and rest consistent, rather than symptom-dependent. By doing this you will be able to gradually increase your ability to carry out everyday activities while slowly cutting down on excessive rest.

- **Spread it**
  Spread rest and activity evenly through the day, in small, achievable chunks. For example, rather than taking a 45-minute walk; take a 15-minute walk 3 times a day.

- **Plan rest**
  It is very important to plan rest as well as activity consistently. Instead of resting when you feel tired, plan rest at set times during the day, for set amounts of time.

- **Avoid daytime sleeping**
  This is more likely to increase sleep problems at night. Establishing consistent bedtime and morning routines can also help (More on sleep in a later session).

Introducing pacing into your routine

Planning ahead is really helpful. Generally, you will plan the coming week’s targets with the CFS/ME team in the diary review session.

- **Find out your baseline**
  Before you start it can be really helpful to keep an activity record for at least a week to see what you are managing to do on a good and a bad day to record a baseline of your activity.

  From this you can set minimum and maximum levels of activity to do regardless of whether it is a good or bad day. The idea being your activity is evenly paced across both good and bad days.

- **What to Expect**
  - **Feeling more tired than usual**
    At first you may find yourself feeling more fatigued. This is normal and temporary! It does not mean that the treatment is not working, or that the illness is getting worse, or that you are damaging yourself. Your body just needs time to get used to this new pattern of planned, consistent rest and activity.

    With time your body will get used to the new pattern and the symptoms will stop by themselves.

  - **Feeling worse before you start an activity**
    You may also feel worse just before starting an activity: again this is normal, and often linked to apprehension. Once you actually start you will probably feel better.
 Feeling tempted to do a bit extra
Sometimes it can be tempting to do more than you had planned, especially on good days. However, stick to your pre-set goals, otherwise this may lead back into a cycle of boom and bust. Instead, see it as an opportunity to build up your reserves!

 Setbacks
Setbacks will occur from time to time, this is perfectly normal. Try not to feel too disappointed if this happens: instead, expect it, and try, as far as possible, to stick to your pre-planned goals. Remember it is the overall trend over weeks that are important, not the odd few off days.

 Keeping Yourself Going
There will probably be times when it becomes hard to keep to your schedule of rest and activity. There are several things you can do to keep yourself going:
1. Remember that progress may seem slow at first, but it gets easier. Also, change may be more obvious to other people than you at first – ask other’s opinions!
2. Try to balance things so that you do enjoyable and not so enjoyable activities on the same day. If you can, begin and end the day with an enjoyable activity.
3. Reward yourself: don’t downplay your efforts: give yourself a pat on the back when you have achieved even small goals!
4. Unexpected events can stop you from being able to follow your programme. That’s ok, just start again with your programme the next day.
5. Use cues to remind yourself to do specific tasks; e.g. asking someone to remind you of important tasks, putting up signs around the house, setting an alarm or kitchen timer to remind you of the time to begin or end an activity.

 Progress Record Diaries
You will find a diary at the end of each week’s section throughout this workbook. The “homework” diaries are an extremely important part of your self-management.

 Why?
1. A daily record of your achievements and your fatigue levels allows you to accurately keep track of progress. Progress can be gradual and easily missed!
2. It helps set, and remind you of daily goals
3. It will help you discuss your progress with the group. Discussion of your homework forms is an important part of your treatment, so remember to bring this workbook to each session!

 Keeping up your diaries may seem a bit overwhelming at first. Filling them in as you go along (e.g. mid-day, late afternoon and before bed) can make it easier.

 When To Move On
We talked earlier about the importance of keeping things manageable, and resisting the temptation to do too much too soon. For this reason you should be careful not to move on to the next set of tasks until the first set can be carried with little or no difficulty. Generally, you will need to practice goals for at least a week before increasing them.
Week 1

What is CFS/ME? Introduction to pacing

Home practice reminder

- Read Week 1 (in small chunks) and share with friends/family/work etc. as appropriate
- Use diary sheets to notice and record periods of activity and rest (see sample diary)
- Colour code diary, i.e. active episodes (e.g. red) and rest episodes (e.g. blue)
- Give yourself regular daily treats or notice the things you enjoy, more. Try different treats
- Set regular times in the day to do relaxation, soft breathing (as we did it today) and your identified treat. Associate these activities with other things you do regularly (e.g. meal times / coffee breaks/comfort breaks)
- If it’s hard to relax or enjoy things try to “fake it ‘til you make it”
- Tell a joke to someone (and if you have an appropriate joke we’ll proof it & tell it to group if you like).
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<td>Went shopping – walked 10 mins</td>
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<td>Watched TV &amp; Slept</td>
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<td>Cleaned kitchen 15 min</td>
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Week 2

Stretch and movement and goal setting
Stretch and movement and goal setting

Physiotherapy for CFS/ME

Stretch & Movement Programme

CFS/ME Service activity guidelines are not over-ambitious exercise programmes.
You will not be advised to “exercise away your exhaustion”, we know that this will only cause you to get worse.
Prolonged rest and inactivity is associated with secondary disability. Bed rest may work for acute illnesses but can cause problems in chronic illness.

- Both activity and rest can be harmful in excess
- Both activity and rest are beneficial in appropriate amounts
- What is appropriate will be different for different people
- What is appropriate may change over time and circumstances.

You, together with the CFS/ME team, will work out what level of activity is appropriate for you. Your personal stretch and movement programme is made up of a series of simple, gentle exercises. Maintaining a planned and paced stretch and movement programme will help produce the best symptom improvements.

Deconditioning – how it occurs

Deconditioning is the normal process of losing fitness, which is associated with decreased levels of activity or exercise.
This is a common problem in many long-term illnesses and can also affect healthy individuals whose lifestyle is predominantly sedentary.
- We lose fitness about twice as fast as we gain it

Deconditioned, unfit muscles (including postural muscles) get tired more quickly, are painful after very little use and lose strength.

- As we become unfit, infrequent bursts of activity (due to unavoidable demands or occasionally overdoing it) cause aches and pains, which may lead us to avoid activity. This creates a vicious cycle leading to increased disability.

The nature of CFS/ME increases the likelihood of deconditioning. Unpredictable “good” & “bad” days lead CFS/ME sufferers into the over-activity – over-rest cycle. This can result in achieving less and less even on better days over time.
What can you do about it?
- Avoid staying in bed for a large part of the day. This causes deconditioning.
- Avoid overdoing it to catch up or make the most of better days. Plan to do a similar amount of activity and exercise every day.
- Avoid basing your behaviour on how you feel (your symptoms). Instead base what you do on a sensible plan. Start pacing.
- Don’t listen to your body. It is likely that you have been listening too closely to what your body has been saying. In long-term illnesses, not only are your body systems out of kilter, but so are your pain and exhaustion messages.
- Activity pacing and sticking to your personal stretch & movement programme will help you avoid the vicious cycles of over activity/rest yo-yoing and deconditioning.

These techniques will also help you regain control of your activity and gradually increase fitness.

Goal setting to increase your activity
Setting goals can be a good way of setting new targets to achieve and a way of measuring your progress and is an important self-management skill.

Working towards goals will mean that you will have to increase the amount of activity you do, but will also help to break the cycles of CFS/ME.

Goals should be personal - this way they will be important to you and you will be more motivated to try and achieve them.

Writing goals is the first step in achieving them
- Creates commitment
- Allows you to see them on paper and revise/update them
- Makes you more focused.

Goals should be SMART:
- **S** Specific, what exactly do you want to achieve?
- **M** Measurable, how can you keep track of your progress? When will you know you have achieved your goal?
- **A** Achievable, is it possible to successfully achieve your goal?
- **R** Rewarding, will reaching this goal give you a sense of enjoyment or achievement?
- **T** Time-specific, what is the time-scale for reaching your goal?
Setting goals takes 3 stages:

1. Decide what you want to achieve (your long term goal)

Example Goals:
- Do the gardening
- Walk with friends
- Use exercise bike
- Go to dance classes
- Improve fitness levels
- Go bowling
- Eat healthy
- Decorate the living room
- Read a book
- Do a car boot sale
- Take more care with appearance
- Clean the house
- Volunteer.

2. Be more specific - can the goal be broken into smaller steps?

Example of a goal:

Goal: Attend computer course
I will (activity) attend course
For at least (time) one hour per week
On (when) Monday
Steps to achieve this
1. Find out when course starts at library
2. Find out cost and length of course
3. Fill in application
4. Plan week so do lighter activities before course so not too tired that day
5. Attend course
When I have achieved this goal I will (reward) have a meal out.

Practise yourself

Identify a goal you would like to achieve and write down the smaller steps involved in reaching your goal.

How realistic is the goal?

Goal:
I will (activity) __________________________
For at least (time) __________________________
On (when) __________________________
Steps to achieve this
1. __________________________
2. __________________________
3. __________________________
4. __________________________
5. __________________________
6. __________________________
When I have achieved this goal I will (reward)
Week 2

Stretch and movement and goal setting

Home practice reminder

- Read each week’s section and share with friends/family etc.
- Use diary sheets to record activity then identify and colour code periods of activity and rest
- Throughout the day practice diaphragmatic breathing to prevent build-up of tension and at first signs of stress
- Establish a regular & reliable daily relaxation practice
- Set times in the day to do your stretch and movement practices and relaxation practices. If it helps record these on your stretch and movement diary. Associate relaxation and stretch and movement activities with other things you do regularly (e.g. meal/getting up times)
- Give yourself regular treats or notice the things you enjoy, more
- Weeks 2-6 – Write your identified goal at foot of activity diaries, record your targeted graded activity (baselines) on a daily basis.
### CFS activity & rest diary

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Your SMART goal is
## CFS Stretch & Movement Programme

(a pictorial version of these exercises is available on request from your Physiotherapist)

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<td>Knee raises (abdominal muscles)</td>
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**Cardiovascular your choice**

NB Remember you can cheat on your pacing baseline either by doing too few movements (i.e. when you don’t feel well) or by doing too many (i.e. on a good day). It is better to do the number agreed and do them well.
Week 3

Managing mood and negative thoughts
Managing mood and negative thoughts

Managing difficult thoughts and feelings in CFS/ME

The way we think about ourselves and our environment has an impact on how we feel and how we behave. Negative or unhelpful thoughts can make you feel even more distressed by your CFS/ME and impact on your recovery.

*Men are disturbed not by things but by the views which they take of them*

Epictetus (AD 55-135)

Identifying and challenging thoughts that keep your mood low

The way we look at the world is to some extent a matter of choice. If our thoughts about things are unhelpful, perhaps we can choose to see things differently. **This is Epictetus’ point.** We can change the way we think. There are no essential truths. There are always several ways of seeing things.

Imagine you heard a bump in the night.....

**If you thought...**

“It’s a burglar!”

**Physical response**

Heart rate increases, ready to fight or run

**Emotion**

Fear

**Behaviour**

Grab a baseball bat!

**If you thought instead...**

“It’s the wind”

**Physical response**

Relaxed

**Emotion**

Indifferent

**Behaviour**

Turn over and go back to sleep

- From this example we can see how we feel about a situation depends on how we interpret it
- How we feel can impact on our behaviour
- How we behave can also impact on how our body feels physically and how we think
- In fact our thoughts, feelings and behaviours are all interlinked!
Managing mood and negative thoughts

What this means for CFS/ME

This means our psychological wellbeing can have an impact on our physical wellbeing and vice versa. For example CFS/ME is likely to have an impact on your mood, but the way in which it impacts on your mood is partly dependent on how you are thinking about it, which will also impact on your physical symptoms...creating a vicious cycle!

The good news is that we can make changes at different points in the cycle that will have a knock on effect on other areas and create a more helpful cycle.

Negative cycle

Our behaviours and our thinking are two of the easier areas to influence and the next sections will give some examples how we can make changes here.
Week 3
Managing mood and negative thoughts

Behaviours
All human beings need BOTH experiences of **achievement** and **pleasure** to keep emotionally well. When someone is suffering from a chronic illness with limited energy like CFS/ME it can be easy to minimise the achievement in completing everyday tasks and to prioritise duties over pleasurable activities.

One aim of this group is to increase your daily pleasure and achievement experiences. These can tie in with your goal planning and pacing projects (and of course with your treats!).

**Questions to ask yourself about achievement**
- How do I feel if I make an effort (in spite of fatigue) to do difficult tasks?
- How often do I give myself credit for the things I achieve?
- What could I do to make it easier to master difficult times?

**Questions to ask yourself about pleasure**
- What things are most enjoyable at the moment?
- How could I do more of these things?
- Are there things that I have stopped doing that I used to enjoy? Is there a way I can start doing these again?

Remember, we need a balance of pleasure and achievement to retain a sense of well-being.

**Questions to ask yourself about**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Pleasure</th>
<th>Achievement</th>
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<tbody>
<tr>
<td>Watched soap rerun</td>
<td>3</td>
<td>1</td>
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<tr>
<td>Vacuumed hall</td>
<td>0</td>
<td>7</td>
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<tr>
<td>Short walk, met Fred</td>
<td>7</td>
<td>7</td>
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</table>

**Take home message**
- Low mood / depression is a natural reaction to chronic fatigue
- It's part of the acceptance process. However, depression can make fatigue worse
- A step to getting better is to increase your pleasure and achievement activities.
- Get rid of the idea that you don’t deserve something (nice) if you have not done anything (productive).

Remember, when you feel a little down and/or things are difficult it is often too easy to rate things negatively – so look for the good in yourself, your experiences and others.

Next, try and increase your pleasure and achievement experiences by planning simple daily tasks. These can tie in with your goal setting and pacing activities.

Start by looking at your life at the moment. What rewards do you get at present? Rate all your daily activities in terms of pleasure and achievement.
Managing mood and negative thoughts

Thoughts - realistic thinking is the goal

Sometimes a negative interpretation of events is appropriate. But always seeing the world negatively, can make you feel even worse. You can begin to feel helpless, hopeless, anxious or paranoid.

It’s not about telling yourself to see the world through rose tinted spectacles. We’re not saying that the way you see the world is wrong. But is it helpful? A more balanced view might help with your emotional well-being. Too many negative automatic thoughts stop you trying to do anything to make things better. This can lead to a self-fulfilling belief.

ACTION

Telling yourself not to do something (not to have negative thoughts) rarely works. That’s why they’re called negative automatic thoughts - they come uninvited; out of habit. But habits can be broken.

Changing thought patterns

1. Identify negative automatic thoughts (NATS) (using a thought diary at the end of this section)
2. Recognise them as thoughts, not facts.
3. Get off the train of thought & watch yourself think
4. Challenge negative thoughts repeatedly by generating realistic alternatives; positive alternative thoughts (PATS) and evaluating the evidence for both – (using the thought diary and alternatives sheet).
Using a thought diary

Use a detailed thought diary to record, recognise then challenge your unhelpful thoughts, using the five steps outlined below (relating to 5 columns of diary – see example thought diary on next page).

1. Record the situation, event or stream of thoughts leading to unpleasant emotion in the first column.

2. Record your negative automatic thought (NAT) in column 2. Rate your belief in this out of 100 (where 0 = “I don’t believe it at all” and 100 = “I believe in it completely”).

3. Identify the emotion in column 3 (i.e. sadness, anger, frustration) and rate its intensity degree in %.

4. Record as many alternative responses (positive alternative thoughts; PATS) in column 4.

5. Finally, return to original negative thoughts (col. 2) and re-rate your belief in it. Then identify how you feel now and rate in % terms.

There are many ways to deal with negative thoughts. We will discuss more ways during the group.
Managing mood and negative thoughts

Home practice reminder

- Read Week 3 (in small chunks) and share with friends/family/work etc. as appropriate
- Use diary sheets to record activity then identify and colour code periods of activity and rest
- Give yourself regular daily treats or notice the things you enjoy, more. Try different treats
- Record the amount of pleasure and achievement you get from the activities you do in your week
- Set regular times in the day to do relaxation, soft breathing (as we did it today) and your identified treat. Associate these activities with other things you do regularly (e.g. meal times / coffee breaks/comfort breaks)
- Practise challenging negative thoughts using the thought diaries. Recognise they are not facts, but one opinion and generate other realistic alternative thoughts
- Keep up your stretch and movement activities and write your goal for the week at the bottom of your activity diary.
<table>
<thead>
<tr>
<th>Situation or event</th>
<th>Automatic thought (negative automatic thoughts)</th>
<th>Emotion</th>
<th>Alternative response (positive alternative thoughts)</th>
<th>Outcome</th>
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</thead>
<tbody>
<tr>
<td>Worry about going back to work</td>
<td>I won’t be able to get the work done or get through day. It’ll make me worse again (85%)</td>
<td>Anxious (80%)</td>
<td>If I go back on a part-time basis as discussed with them and stick to the agreed work-load &amp; hours I should manage. I need to tell workmates about illness and accept their help &amp; my own limits</td>
<td>Belief in automatic thought now (40%)</td>
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<tr>
<td>Getting ready to go into town to do food shopping</td>
<td>I feel so exhausted. I’ll never get better (75%)</td>
<td>Fed up (50%)</td>
<td>There’s no reason why I shouldn’t get better in the future, others have. I’m already noticing a change in how I cope with things. It’s OK just to do a little shop today then order on line or get stuff another day. If I’m tired when I get home we’ll have a simple meal</td>
<td>Belief in automatic thought now (60%)</td>
</tr>
<tr>
<td>Sitting at home watching TV</td>
<td>People don’t really believe I’m ill, especially at work they think I’m making it up or lazy (80%)</td>
<td>Angry &amp; Frustrated (60%)</td>
<td>It doesn’t matter what they think. I know I’m not well &amp; my family believe me. Meeting others with CFS/ME has helped and I know the NHS validates the condition. I know lazy selfish people do NOT get this condition. I’ll ring up someone from the group to see how they are and then do my relaxation practice</td>
<td>Belief in automatic thought now (65%)</td>
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</table>
### Thought Diary

<table>
<thead>
<tr>
<th>Situation or event</th>
<th>Automatic thought (negative automatic thoughts)</th>
<th>Emotion</th>
<th>Alternative response (positive alternative thoughts)</th>
<th>Outcome</th>
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## CFS activity & rest diary

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<tr>
<th>Time</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
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Your SMART goal is
CFS Stretch & Movement Programme
(a pictorial version of these exercises is available on request from your Physiotherapist)

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<th>DAY</th>
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<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
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<td><strong>Exercises - Warm up</strong></td>
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<td>Knee raises (abdominal muscles)</td>
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<td>Arm stretch across chest</td>
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<td>Arm stretch to the ceiling</td>
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<td>Star steps or star jumps</td>
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<td><strong>Cardiovascular your choice</strong></td>
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NB Remember you can cheat on your pacing baseline either by doing too few movements (i.e. when you don’t feel well) or by doing too many (i.e. on a good day). It is better to do the number agreed and do them well.
Week 4

Stress and anxiety management
Managing stress in chronic illness

Stress management is an important part of managing CFS/ME. Stress is normal, but needs to be managed. Stress affects everybody and comes from a variety of sources:

1. Life events e.g. marriage, divorce.
2. Daily hassles e.g. work, kids, driving, form filling.
3. Emergencies e.g. saving someone from danger.

Although there are various common themes, stress is an individual experience and affects us all differently.

Stress affects us in three main ways:

1. Bodily sensations - physiology
2. Psychological effects of stress
3. Behavioural changes

1. Bodily sensations - physiology

When we are afraid (and when we are very stressed or anxious) we undergo bodily changes designed to prepare us for action. These are evolutionary responses that were appropriate to save our caveman ancestors from predators. However they are not useful for the stress and anxiety that comes with, for example, an overdue electricity bill.

Under stress:

- Heart rate speeds up so more blood gets to muscles and vital organs
- Breathing speeds up (hyperventilation) to get more oxygen in muscles (ready to run or fight)

- Stomach shuts down and blood is diverted to the main muscles
- Sweat is produced
- Muscles are tensed ready for action
- All senses are ‘turned up’ to detect danger. This includes awareness of pain although adrenaline initially reduces the awareness of pain.

These physiological mechanisms translate into the physical symptoms or sensations of stress and anxiety.

- Dry mouth, difficulty swallowing, choking feeling
- Blurred vision, poor concentration, headache
- Stomach churning, tightness, butterflies in stomach, nausea
- Diarrhoea
- Cold sweat
- Rapid pulse, heart pounding, palpitations
- Rapid breathing, breathlessness, feeling faint
- Cold clammy hands, tingling, pins & needles
- Numbness
- Tension, tiredness, aches & pains
- Pains in muscles, knees knocking
- Trembling, shakes
- Feeling distant
- Sensitive to pain.

Remember these symptoms are all related to a normal stress response. They will not hurt you but they are very uncomfortable. They will go away as you recover and can be controlled.
2. Psychological effects of stress

- Decreased concentration (except for danger & problems)
- Decreased memory
- Decreased decision making
- Racing thoughts (concentrated on danger & problems)
- Poor sleep
- Decreased self-confidence
- Feelings of inadequacy & ‘madness’
- Sense that you are different or not like others / changed personality
- Minor problems (i.e. those you might once have ignored) seem really big
- This may lead to feelings of failure or despair
- You may be tempted to try to escape the problem (avoidance) but in the long term this usually makes things worse.

3. Behavioural changes

- Unable to listen to others
- Feeling unsatisfied
- Restless and fidgety
- Feeling helpless and hopeless
- Bad tempered and irritable
- Lose your sense of humour
- Lose your sense of fun.

Anxiety thoughts

It’s not just events that evoke this stress response. Thoughts can also trigger them.

“I can’t possibly get enough money to buy everyone Christmas presents!”

“That noise downstairs must be a burglar!”

“I’m letting my family down by feeling ill all the time.”

Anxiety thoughts can be particularly harmful because they are often very quick or become habitual so we don’t identify them. This means we have no explanation for the uncomfortable stress symptoms, we just notice the feelings.

In a real emergency excess energy/stress reactions are used up appropriately.

Afterwards we think: “thank goodness that was close but I’m safe now”

This also helps to turn the stress response off.

However, this won’t usually happen with chronic worries & anxiety.
Stress and anxiety management

Recap
The way in which we think about a situation or event can have big effects on our bodies’ physical response, our behaviour and our emotional outlook. This is because as we saw last week thoughts, physiology, behaviours and emotions are all linked; each has a knock on effect on the other.

What can you do to decrease your stress levels?
1. Identify / recognise the stress response when it occurs.
2. Remind yourself that the signals of the stress response do not indicate illness but demonstrate a good adrenaline function.
3. Practice focused diaphragmatic breathing a minimum of 5 times a day to dissipate tension.
4. Practice relaxation techniques at least once every day.
5. Practice a pattern of regular exercise and effective rest every day.
6. Practise positive self-talk.

Other stress busters
1. Try a problem solving technique.
2. Share your worries with supportive friends or relatives.
3. Delegate.
4. Slow the pace down.
5. Only expect from yourself what you might expect from a friend with a debilitating illness.
6. Drop your standards - are your expectations setting you up to fail?

The impact of stress affects different people differently

In some: The situation gets worse and worse until the stress response builds up to a panic attack (believe they will die - in fact anxiety & panic attack symptoms cannot hurt them).

Others: Develop chronic stress. They have adrenaline effects all the time and feel pretty drained? Long-term: lose confidence & become increasingly fearful.

Still others: Experience sudden or acute episodes of anxiety. This usually coincides with sudden build-up of adrenaline due to onset or increase in stressors. Experienced as a sudden feeling of weakness, illness, fear, anger – not sure why.
Read Week 4 (in small chunks) and share with friends/family/work etc. as appropriate.

Use diary sheets to record activity then identify and colour code periods of activity and rest.

Give yourself regular daily treats or notice the things you enjoy, more. Try different treats.

Set regular times in the day to do relaxation, soft breathing (as we did it today) and your identified treat. Associate these activities with other things you do regularly (e.g. meal times / coffee breaks/comfort breaks).

Keep up your stretch and movement activities and write your goal for the week at the bottom of your activity diary. Regular exercise is a natural stress reliever.

Recognise the stress response when it occurs. Practise diaphragmatic breathing and relaxation techniques when feeling stressed. Review stress buster techniques and consider if you can apply any to your life.

Practise challenging negative thoughts using the thought diaries. Recognise they are not facts, but one opinion and generate other realistic alternative thoughts.
**Week 4**

### CFS activity & rest diary

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Your SMART goal is
## CFS Stretch & Movement Programme

*(a pictorial version of these exercises is available on request from your Physiotherapist)*

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**NB** Remember you can cheat on your pacing baseline either by doing too few movements (i.e. when you don’t feel well) or by doing too many (i.e. on a good day). It is better to do the number agreed and do them well.
## Thought Diary

<table>
<thead>
<tr>
<th>Situation or event</th>
<th>Automatic thought (negative automatic thoughts)</th>
<th>Emotion</th>
<th>Alternative response (positive alternative thoughts)</th>
<th>Outcome</th>
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Sleep and relaxation
Sleep

We spend about one-third of our life sleeping and it is vital for a healthy body and mind. Sleep forces us to rest, allowing tissue to repair and our energy.

Effects of poor sleep

- Fatigue
- Depression
- Anxiety
- Get more infections
- More sensitive to pain
- Increased appetite
- Poor concentration
- Slower reaction times
- Poor memory.

How can you improve your sleep?

Sleep routines

- Try to wake up and go to bed the same time each day
- Avoid day time naps, or limit them to no more than 30 minutes
- Create a pre-sleep ritual (e.g. bath, relaxation, reading) to relax before bed.

Sleep environment

- Try and keep bed just for sleeping (and sex) no TV, computer, reading etc.
- If an uncomfortable bed or bedding is the problem… change it!
- Ensure the room temperature is not too hot or too cold
- Sharing a bed may be a problem- try sleeping alone and see if this is better for you. Changing environments and sleeping in a different room can also help
- Turn your clock away from you and replace a ticking clock with a silent one- it avoids ‘clock watching’
- Keep the room quiet- block out distracting noises (use ear plugs etc.)
- Dim the lights for a few hours before bedtime, darkness releases hormones that make you sleepy.

Exercise

- Regular exercise helps you fall asleep more quickly and sleep more deeply
- Try to exercise in the afternoon or early evening and avoid exercising before bedtime – you may need to wind down for 30-60 minutes before bed
- Daily exposure to outdoor sunlight (e.g. going for a walk).
Sleep and relaxation

Drink
- If you wake needing the toilet during the night try to limit your fluid intake for a couple of hours before going to bed
- Avoid alcohol, it causes poor quality sleep
- Cut down/out caffeine (found in chocolate, coffee, tea etc.).

Nicotine
- Nicotine is a stimulant and can therefore affect your sleep
- Insomnia is often reported in smokers
- Smoking raises the blood pressure, speeds up the heart rate and stimulates brain activity, all of which make it harder to sleep.

Eating habits
- Don’t eat too late as digestion can affect sleep
- Have a light evening meal that contains protein (such as lean chicken or fish) to stop you waking up hungry in the night
- Spicy foods can cause heartburn or stomach discomfort during the night
- Having a carbohydrate-based snack if hungry before bedtime may help you to sleep because it triggers the release of serotonin (a hormone that aids sleep).

Attitudes/beliefs
- Worrying in bed will prevent you getting to sleep, try to set some ‘thinking time’ (20-60 mins) during the day to focus on any worries you may have
- Keep a worry diary at the side of your bed, for noting worrying thoughts that happen at night and deal with them in the morning.

Prescribed medication
- Some prescribed medication can cause sleep disturbance, ask your doctor or pharmacist to review your medication to see if this is the case
- Sleeping tablets may help. However consult with your GP before starting new medication.

What if you still can’t sleep?...
If you don’t fall asleep within 15 to 30 minutes get up and go to another room. Read a book, watch TV or try relaxation techniques until you feel tired enough to sleep. Lying in bed for longer than 30 minutes trying to sleep rarely leads to sleep.
Sleep and relaxation

Relaxation - a pain management skill and stress buster
Relaxation refers to relaxed muscles or peaceful thoughts. It is characterised by feelings of peace and release from tension, anxiety or fear.

Relaxation techniques are used as a:
- Preventative measure - to protect the body from stress and health problems (protects the organs from the effects of stress)
- Treatment - to help relieve stress and tension in conditions such as hypertension, insomnia, panic attacks, headaches and chronic pain
- Coping skill - to calm the mind and allow clearer thinking.

Being able to use these techniques is a skill that needs to be practiced and mastered. You should set time aside in your daily routine (at least 20 minutes) to practice relaxation skills. There are a variety of techniques available, some of which we will teach you on this programme...it’s about finding the right techniques for you.

Some points about relaxation....
- Relaxation should be completed in a quiet and warm environment. Gentle background noise, such as relaxation music, and dimmed lighting may help
- Relaxation techniques are often completed lying down. But can also be done sitting in a chair. It is most effective if you are in a position where your body can be fully supported so that you can fully relax your muscles
- Most people find relaxation more effective with their eyes closed. However if you are uncomfortable with this you should ensure that there are no visual distractions (i.e. blank wall, TV off etc.)
- Do not practice relaxation if you are hungry or have just eaten - relaxation is best completed at least one hour after a light meal
- Relaxation should help you feel calm in body and mind. Relaxation however is not the same as hypnosis and you will not lose consciousness at any point
- Try not to fall asleep while you are practising relaxation techniques - relaxation should be something that you are in control of.
Sleep and relaxation

Breathing techniques
When you are asleep all your muscles are relaxed and your breathing naturally slows and becomes deeper. This is the type of breathing that is used in breathing techniques. These exercises can be carried out as a stress management technique or at the start of a relaxation session. We will practice breathing techniques at the start of each relaxation session.

1. First, remove any restrictive clothing (such as belt or shoes).
2. Lie on your back or sit in a supportive chair with your feet a comfortable width apart and your eyes closed.
3. Place one hand on your stomach, just below your navel, and the other hand on your chest.
4. Breathe slowly and deeply, in through your nose then slowly out through your mouth, thinking about the sound of each breath as you breathe in and out.
5. As you breathe you should notice that the hand on your stomach gently rises and falls while the hand on your chest remains quite still.

Take time to practice this and ensure that you have mastered the technique for deep breathing.

Incorporating relaxation into everyday life
- Try not to rush - you will achieve more if you stop to think about what you need to do and are calm
- Make sure that you take regular short breaks to relax, stretch muscles etc.
- Plan time for yourself in your daily routine to do things that you enjoy and find relaxing (e.g. reading, going for a walk etc.)
- Try to notice any muscle tension and deliberately relax your posture - drop your shoulders, relax your arms, unclench your hands, sit back in your chair etc.
- If you don’t have time, make time! Plan time to relax in your daily routine.

“The time to relax is when you don’t have any time”
Sydney Harris
Read Week 5 (in small chunks) and share with friends/family/work etc. as appropriate

Use diary sheets to record activity then identify and colour code periods of activity and rest

Set regular times in the day to do relaxation, soft breathing (as we did it today) and your identified treat. Associate these activities with other things you do regularly (e.g. meal times / coffee breaks/comfort breaks)

Keep a sleep diary to help identify any aspects of your sleep routine you need to change

Try changing aspects of your sleep routine/environment/sleeping habits that you have identified trigger a bad night’s sleep. Try these out for a few nights and record in your sleep diary to see if they make a difference

Keep up your stretch and movement activities and write your goal for the week at the bottom of your activity diary.
### CFS activity & rest diary

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Went to sleep

Your SMART goal is
# CFS Stretch & Movement Programme

(a pictorial version of these exercises is available on request from your Physiotherapist)

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**Cardiovascular your choice**

**NB** Remember you can cheat on your pacing baseline either by doing too few movements (i.e. when you don’t feel well) or by doing too many (i.e. on a good day). It is better to do the number agreed and do them well.
## Sleep diary

Use this sleep diary to record information about your sleep (i.e. what you were doing before you went to bed; food you ate, number of times woke during the night.)

<table>
<thead>
<tr>
<th>DAY</th>
<th>Meal before bed</th>
<th>Drinks before bed</th>
<th>Activities before bed</th>
<th>Time went to bed</th>
<th>Time(s) got up</th>
<th>Comments/Possible changes</th>
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Read the tips provided to improve your sleep and put a star against any you could try based on the problems identified. Test whether making the change has any effect on your sleep. You may need to try a few things before you find something that makes a difference. Keep experimenting as there may be more than one factor affecting your sleep.
Week 6

Pain and overcoming setbacks
### Pain and overcoming setbacks

#### The cycle of pain

- **Pain**
- **Fatigue**
- **Depression**
- **Muscle tension**
- **Psychological stress/anxiety**

#### The cycle of pain

- **Pain is DECREASED when...**
  - You are not thinking about it (i.e. busy, distracted).
  - You are relaxed (physical tension makes pain worse).
  - You are not tired.
  - You believe it is not serious.

- **Pain is INCREASED when...**
  - You are tired.
  - You are worried about it (what it means, how long you have had it).
  - You pay it attention
  - You feel depressed

#### What can you do about it?

- Continue with usual activities of daily living (walking, housework, working etc.) as much as able to
- Planning and pacing techniques
- Keep active - set goals/contract, do exercise etc.
- Make an effort - visit friends, go to cinema etc.
- Review medication
- Consider alcohol consumption
- Practice relaxation techniques.
Aches, pains and strange sensations
- People with CFS/ME seem to experience these more than others. However it is not always clear why
- As you get better these symptoms will improve
- These experiences DO NOT indicate an undetected medical problem
- These experiences DO NOT mean physiological damage is happening
- Some may be caused by hyper vigilance.

Pain threshold and pain tolerance
Pain Threshold is the point at which your brain decides that a sensation is “painful”
Pain Tolerance is the greatest intensity of painful stimulation that an individual is able to bear.
- Pain management strategies target an individual’s pain tolerance
- Pain tolerance is different for everyone
- Pain tolerance changes across different situations
- Pain threshold differs across cultures
- Individual’s pain tolerances change across time and circumstance.

The brain varies the pain tolerance according to what is going on (i.e. attention)
If we paid attention to everything we would become too confused for survival. It is our brain’s job to ignore some messages-turn attention off.

It is normal to attend to things we are scared of. When we turn our attention fully onto a specific pain/sensation message we are hyper-vigilant. For example, we ‘experience’ an ulcer as heart attack/toothache is worse at night.

Hyper-vigilance makes the pain feel more intense.

Coping with setbacks and what to do if symptoms flare up…

1. Don’t panic!
- Remember that setbacks are not a disaster (even if it feels like one at the time). Many people with CFS/ME go through them and get over them. You CAN overcome the setbacks, given time and perseverance
- Hang on in there! Even if you can’t get over the setback immediately, don’t give up! You will prevail!

2. Learn from setbacks
- Make use of your setbacks. Setbacks can teach you what things make you feel worse, and allow you to practice and strengthen what you have learnt
- Even if you have several setbacks, over time you will become more and more able to deal with them quickly and effectively.
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3. Take sufficient medication
- If you are unsure what medication/doses you should be taking seek advice from your pharmacist
- If you think you need more medication than you are currently on see your GP
- Medication is most effective if taken regularly, as prescribed. Keep pain relief medication handy for when you need it
- Test your medication (in consultation with your GP) - try decreasing the dose slightly and use a pain score to monitor what effect it has (0=no pain up to 10=severe pain). You might find you can manage on a lower dose, meaning you can go to the higher dose when you have a flare up.

4. Use distraction techniques
- Keep busy and occupied - remember your activity diary...how you are feeling (your mood) affects your perception of pain
- Try not to worry - you have had flare-ups before and the pain will settle down. You have more knowledge and coping skills now! Maybe try some of the relaxation techniques learnt during the programme.

5. Rest
- While it is important to exercise and continue your daily activities, it is also important to rest
- If you are experiencing a flare-up plan more rest periods into your week than you usually would
- Resting is not the same as stopping! Still try to keep active and after a few days start to gradually increase your activities again.

6. Think positively
- Don’t get into the trap of thinking the worst (negative thinking). Your pain will improve and things will get better...you can take control
- Setbacks don’t mean the CFS/ME management programme hasn’t worked. They are a problem to be solved. Use what you have learnt to identify what caused the setback. Start a daily activity diary, and then create a manageable plan of activity and rest
- Don’t feel that you have to start again from scratch. Believing that you are back to square one will make you feel worse, so tell yourself that if you could overcome some of your difficulties before you can certainly do it again now!
- Remember that what you think affects how you feel and behave. If you can try to think positively you are more likely to be able to be in control of your symptoms and their impact on your life.

7. Get back to your exercise and functional activities
As you get better think back to your goals and adjust your exercise gradually to get back on track - no boom or bust!
- Use an activity diary to plan and pace your week so that you get back to your usual routine or to set yourself some goals to help you increase your activity levels again.
Tips for maintaining your exercise and activity levels

- Keep your exercise booklet close at hand
- Write an action plan of things you want to remember when you have a flare-up
- Always set yourself goals/targets and remember to keep them SMART
- Set short-term goals that are achievable for you
- Set long-term goals that are important to you and will give you a sense of achievement
- Plan weekly targets and record what you have done
- Choose exercise and activities that are important to you
- Reward yourself for achievements
- Pace your activity, making sure that you increase your activity levels gradually
- CSF
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CFS/ME self-management set back plan

List at least 3 things you have found useful from the CFS/ME course (or elsewhere). Include strategies you are using now.

1) 

2) 

3) 

Strategies for managing CFS/ME you are not using but may use in future. Include things you have found difficult to implement or those that other CFS/ME group members have used successfully.

My personal Set-back plan (relapse tool-kit) What I am going to do if things get worse.
Support groups

Manchester ME Society
Mary Ellis
- Mary.ellis44@tiscali.co.uk
- 07984 756221 (after 1pm only)

Bury and Bolton ME/CFS Support Group
Pam Turner
- 01204 793 846
- www.mesupportgroup.co.uk
Nine meetings a year & book library; quarterly newsletters; monthly meeting reminders; social group & internet chat group; link-up contact service; free yoga sessions & benefit advice. Local meetings are also held in Radcliffe and Bury monthly. Also have a manual wheelchair and electric scooter available to borrow.

Stockport ME Group
Jean Holt
- www.subn.org/stockport_me_group/default.shtml
- 0161 432 0390 (weekdays 10am - 4pm)

Salford and Central Manchester ME (CFS) Group
- http://manchestersalfordmegroup.wordpress.com

Helplines

ME Information and Support Line
- 0844 576 5326
- mecontact@meassociation.org.uk
Telephone helpline available everyday:
  - 10.00am - 12.00pm
  - 2.00pm - 4.00pm
  - 7.00pm - 9.00pm

Action for ME Telephone Support Service
- 0845 123 2314
Monday - Friday 11am - 3pm
Closed on bank holidays

Greater Manchester Fit For Work
- www.pathwayscic.co.uk