Myalgic Encephalomyelitis
- Chronic Fatigue Syndrome (ME-CFS)

Information for patients
Physiotherapy Department
ACKNOWLEDGEMENTS

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## Contents

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Fatigue Syndrome</td>
<td>4</td>
</tr>
<tr>
<td>Lifestyle Management</td>
<td>6</td>
</tr>
<tr>
<td>Relaxation</td>
<td>8</td>
</tr>
<tr>
<td>Stress Management</td>
<td>14</td>
</tr>
<tr>
<td>Sleep Management</td>
<td>16</td>
</tr>
<tr>
<td>Getting Active</td>
<td>18</td>
</tr>
<tr>
<td>Exercise</td>
<td>20</td>
</tr>
<tr>
<td>Making changes</td>
<td>21</td>
</tr>
<tr>
<td>Goal Setting</td>
<td>22</td>
</tr>
<tr>
<td>Pacing</td>
<td>23</td>
</tr>
<tr>
<td>Preventing and Minimising Setbacks</td>
<td>29</td>
</tr>
<tr>
<td>Summary</td>
<td>31</td>
</tr>
</tbody>
</table>
Chronic Fatigue Syndrome

Myalgic Encephalomyelitis - Chronic Fatigue Syndrome (ME-CFS) are ‘umbrella’ terms for a condition where sufferers experience long term disabling tiredness (fatigue), which is not caused by any other known medical condition. It is estimated that 1 in 300 people in the United Kingdom are affected. It is twice as common in women than in men and commonly develops between the early twenties to mid forties age range.

The cause of ME-CFS is not known. A popular theory is that a viral infection may trigger the condition. It is not known why the symptoms of a virus persist despite no evidence of infection. Many ME-CFS sufferers' symptoms do not start with a viral infection.

Diagnosis

Diagnosis of ME-CFS is by a Doctor dependant on the symptoms you have. All the tests that are normally performed to rule out other causes of fatigue are normal in ME-CFS sufferers. The medical definition of ME-CFS is the sufferer should have the symptoms for 6 months.

Symptoms

Fatigue

Persistent fatigue of new onset starting at a point in time and causing limitation in activities compared to previously. It can be both physical and mental fatigue. Fatigue is:

- Not eased much by rest.
- Not due to tiredness following overexertion.
- Not due to muscle weakness.
- Not due to loss of motivation or pleasure which occurs in people who are depressed.

Made worse by activity (post exertional malaise), which may not develop for several hours or more after activity. It may develop the following day.

Mental

- Poor concentration
- Decreased attention span
- Poor memory for recent events
- Difficulty planning/organising thoughts
- Difficulty finding ‘right words’ to say
- Feeling disorientated

Sleeping Difficulties

- Broken sleep
- Altered pattern

Pains

- Muscular (myalgia)
- Joint pains
- Headaches
Sore Throat

- Tenderness near lymph glands

Intolerances And Sensitivities

- Food
- Alcohol
- Noise
- Bright light

Gut Symptoms

Similar to Irritable Bowel Syndrome

- Excess wind
- Bloating
- Alternating diarrhoea and constipation
- Abdominal pain
- Nausea

Severity

Most ME-CFS sufferers have mild to moderate severity.

Mild

- able to take care of yourself and do light domestic tasks but with difficulty
- you can manage a full time job but have to take days off
- all leisure activities have been stopped to ensure you stay at work
- the days off are used to rest to enable you to cope

Moderate

- mobility is reduced
- activities of daily living are restricted
- ‘peaks and troughs’ with activity levels and severity of symptoms
- Stopped working
- Need rest periods during the day, often sleep in the afternoon
- Night time sleep is disturbed

Severe

- carry out minimal daily tasks
- problems with mental processes such as concentrating
- may not be able to leave the house
- mobility is severely affected

Very Severe

- unable to mobilise
- unable to carry out personal activities of daily living
- unable to tolerate noise
Lifestyle Management focuses on tackling the secondary effects of illness and managing the symptoms to improve mood, self esteem, physical and psychological fitness.

- Stress management, mood control, relaxation
- Pacing, planning and sleep management
- Knowledge
- Goal setting
- Getting active exercise
- Communication skills
- Overcoming barriers and finding solutions
- Managing relapse
- Looking ahead

All the above sections can be interlinked together, which will be demonstrated throughout the programme. The sessions are all directed at changing your current situation for the better. ‘Transition’ can be used to describe this. When change occurs, people go through 7 stages of ‘transition’. All the stages are completely normal reactions to changes in people lives or circumstances – good or bad.

**Periods of Transition**

**Shock**
- feeling overwhelmed or blocked
- unable to plan or act
- no feeling/numb
- if event expected or positive, shock less intense

**Denial**
- denying change or trivialising it
- seen as undesirable or unhealthy reaction
- important to recognise as normal and necessary

**Depression**
- increased awareness of reality of situation

**Anger**
- facing up to change and consequences
- feeling really low and not knowing now to cope with new situation is common

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Myalgic Encephalomyelitis - Chronic Fatigue Syndrome
Acceptance

- accepting reality and letting go of the past
- accepting change
- may be difficult time as people can experience deep feeling of despair and loss
- not knowing how to move forward

Finding out ways to cope

- gradually trying out new things and new ways of coping

Making sense of things

- trying to understand how and why things are different
- standing back from the experience and attempting to make sense of it all

Moving on

Periods of transition will be different for every person. Some people won’t pass through all the stages of transition. It is normal for some people to stay at the one level.

Everyone will be at different stages of acceptance. Our beliefs and attitudes may change throughout our lives.

Examples

<table>
<thead>
<tr>
<th>Unhelpful Beliefs</th>
<th>Helpful Beliefs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid physical activity is best way to cope with the situation</td>
<td>Managing activity levels and staying active and involved helps me cope</td>
</tr>
<tr>
<td>Complete rest is the best way</td>
<td>Staying rested by taking appropriate rest breaks throughout the day</td>
</tr>
<tr>
<td>It is not safe for a person with my condition to be active</td>
<td>Knowing safe limits I can plan appropriate levels of activity</td>
</tr>
<tr>
<td>I can’t do things normal people do because...</td>
<td>With some thought and planning I could do normal things</td>
</tr>
<tr>
<td>My situation is a medical problem and there’s nothing I can do about it</td>
<td>There’s lots of things I can do to manage my situation</td>
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Relaxation

Relaxation is a very important part of managing ME-CFS. Relaxation can be beneficial and make you feel good. It can often take a little time to practice and learn relaxation but lots of people feel that the effort is well worth while.

How does it work?

Relaxation will allow your body to relax and allow you to unwind. There are many different benefits to relaxation, which is listed below.

Physical responses to relaxation

- Clear thinking
- Breathing easier
- Relaxed muscles
- Improved digestion
- Heart rate slows down
- Warm hands, dry hands
- Eyes relaxed
- Improved balance

Sensations of relaxation

- Body may feel lighter or heavier
- Tingling sensations
- Warmth
- A sense of floating or expansiveness
- Reduced discomfort
- Blissfulness
- Sense of timelessness
- Easy breathing

Benefits of regular deep relaxation

- Reduced sense of urgency in life
- Easing of tensions
- Lowered anxiety
- Less irritability
- Improved physical coordination and activity
- Greater energy, productivity and work satisfaction
- Increased clarity of thought
- Enhanced creativity
- Greater self-acceptance
**Relaxing activities**

There are many activities that people find relaxing and these include both physical and psychological. Some are included in the table below:

<table>
<thead>
<tr>
<th>Physical</th>
<th>Psychological</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warm bath, sauna or steam bath</td>
<td>Breathing exercises</td>
</tr>
<tr>
<td>Gentle massage</td>
<td>Mindfulness exercises</td>
</tr>
<tr>
<td>Reading</td>
<td>Meditation</td>
</tr>
<tr>
<td>Listening to music</td>
<td>Visualisation/memory exercises</td>
</tr>
<tr>
<td>Time with family/friends</td>
<td></td>
</tr>
<tr>
<td>Painting/drawing</td>
<td></td>
</tr>
<tr>
<td>Aromatherapy</td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
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</tbody>
</table>

It is likely you use a mixture of some of these activities already, or you can remember using them before you had pain. It is possible to modify the activities you may have previously undertaken, so that you can still be involved and active in some way.

**When should you relax?**

It is suggested that you put aside several sessions per day dedicated purely to relaxation. It is important that you find time to relax when it suits you, but this should also take into consideration the times when you find your symptoms most difficult to manage. For instance:

**Morning:** This time can be ideal to release muscular tension built up from the previous night and prepare you for the day ahead.

**Midday:** This will allow you a rest period between morning and afternoon.

**Evening:** To prepare to unwind for bed and enable sleep and rest.

For many people, it feels wrong to be spending time relaxing when they should be doing things. There is no medication as powerful as the relaxation response for dealing with stress and the symptoms of stress. The relaxation times are important with your pacing.

**Getting started**

Find a place where you can be warm and comfortable. You can choose which position is best for you. It might be a good idea to unplug the phone and dim the lights so that you are not disturbed and can focus on relaxing body and mind. Over time it will become easier to relax in many different environments and positions.

**Techniques**

There are many different techniques you can use to help to relax, some of which are more formal than others. You will begin to notice the changes in your body as you gradually begin to manage your pain.
**Diaphragmatic Breathing**

Diaphragmatic breathing or ‘belly breathing’ is a natural breathing technique which all of us automatically adopt from birth as the diaphragm is the most efficient muscle of breathing. People who live with higher levels of anxiety, anger, panic or stress e.g. whilst dealing with chronic pain, can begin to change their pattern of breathing. Mild breathing complications (over-breathing and/or shallow-breathing) are extremely common.

Breathing more quickly, irregularly or deeply, can lead to oxygen being pumped around the body faster than normal, leading to tingling sensations, faintness and dizziness. If your breathing can be controlled, the severity of symptoms (anxiety, fear etc.) may be reduced and conditions managed more successfully.

Diaphragmatic breathing is intended to help you use the diaphragm correctly while breathing to:

- Strengthen the diaphragm
- Decrease the work of breathing by slowing your breathing rate
- Decrease oxygen demand
- Use less effort and energy to breathe

**How to practice diaphragmatic breathing**

- Find a quiet place free from distractions. When you first learn the diaphragmatic breathing technique, it may be easier for you to follow the instructions lying down. Loosen any tight clothing and remove glasses.
- Lie on your back on a flat surface or in bed, with your knees bent and your head supported. You can use a pillow under your knees to support your legs. Place one hand on your upper chest and the other just below your rib cage. This will allow you to feel your diaphragm move as you breathe.
- Try and make sure your breathing is neither too deep nor too shallow; keep your breathing nice and calm.
- Breathe in slowly through your nose, imagining you are filling up a bottle so that your lungs fill from the bottom. As you inhale you should feel your stomach rise up as you count to three. The hand on your chest should remain as still as possible.
After a short pause, slowly exhale through your mouth while counting to three. Your stomach should fall back down as you breathe out.

As you gain more practice, you can try the diaphragmatic breathing technique while sitting in a chair. Sit comfortably, with your knees bent and your shoulders, head and neck relaxed.

How often can I practice this breathing?
At first, practice this exercise 5-10 minutes about 3-4 times per day. Gradually increase the amount of time you spend doing this exercise.
Progressive Muscular Relaxation

Progressive muscle relaxation is a systematic technique for managing stress and achieving a deep state of relaxation. It was developed by Dr. Edmund Jacobson in the 1930s. He discovered that a muscle could be relaxed by first tensing it for a few seconds and then releasing it. By tensing and releasing various muscle groups throughout the body helps to produce a state of relaxation.

- Settle yourself into a comfortable position with pillows adequately supporting your head and knees. Loosen any tight clothing; make sure your whole body is supported. Arms resting by your side, your legs straight and feet comfortably resting.
- Begin with your breathing, noticing your abdomen rise and fall with each breath; focus on your normal steady breathing. As your breathing becomes more relaxed and restful, take your awareness up to your face. Tense the muscles in your face and hold for a few seconds, then release the muscles.
- Notice the tension just washing away. With each tense and release cycle, you'll notice it becomes easier and easier to release and relax each muscle group.
- Now, you should move your awareness to the shoulder and neck area. Tense the muscles in the neck by pressing the shoulders towards the ears and holding for a few seconds, and release. Notice the difference between a tense muscle and a relaxed muscle as you go through the process.
- Bring your awareness to the muscles in the arms. Tense the muscles in both of your arms by curling the arms up towards your shoulders and holding for a few seconds towards your chest. Remember to inhale through the nose and exhale through the mouth, this can release any residual tension in the arm.
- Now, bring your awareness to the muscles in the hands. Tense the muscles in the hands by clenching them into a tight fist, holding for a few seconds and then releasing.
- Notice the muscles in the upper back, around the shoulder blades. Tense the muscles in the upper back by pressing the shoulder blades together and holding for a few seconds before releasing.
- Now, notice the muscles in the abdomen and low back. Tense the muscles in the abdomen by imagining trying to touch the belly button to the spine, pressing the low back to the chair and holding for a few seconds and then releasing.
- Now on to the feet. Tense these muscles by pulling the toes up towards the knees, and again holding for a few seconds, and then releasing the calf muscles. Remember to inhale through the nose and exhale through the mouth, this can release any residual tension in the muscles.
Visual Relaxation Exercise

Imagine a picture of a beautiful place — a beach, garden, comfortable room, etc. Choose a place that looks relaxing.

Once you’ve chosen a picture of a place you’d like to visit pretend that you are going to take a vacation there without leaving the room. If you’re comfortable, you can close your eyes for a moment.

Imagine yourself in the beautiful place you’ve chosen. Think of what you would do there. You might be walking, or lying down and resting, swimming, or simply sitting quietly. You are alone, but you are completely safe.

Imagine any sounds that might be there — birds, a breeze, rippling water, or an ocean crashing. Is the sun shining? If you’re indoors, you might notice the way the light falls. Your place is perfect and complete. You have everything you need. You can create this place to be anything you’d like it to be.

Now, you can begin to let go of your beautiful place, knowing that you can return for a short vacation at any time. This safe place is always within you. As you bring your attention back to the room, take this feeling of calm, peace and relaxation with you, and find it within yourself whenever you need to.
Stress management

Stress is a normal part of everyday life. Stress can help us keep motivated to do things and help us deal with emergency situations. If stress levels become too high or occur over a prolonged period of time, we can begin to struggle. This can happen when people experience ongoing problems such as chronic illness, unexplained symptoms, altered relationships or problems at work/home. Not dealing with the problems that can be encountered can exacerbate your current symptoms and also lead to secondary symptoms such as sleep problems and loss of appetite.

The body prepares itself to react in emergency situations:
- Eyes become focussed/hard
- Saliva in mouth dries up
- Heart speeds up
  - To pump more blood to muscles
- Breathing becomes faster and shallow
  - To get more oxygen to muscles
- Main muscles tense up
  - Ready for action
- Blood supply to hands and feet shut down
- Sweat produced
- Blood shunted away from non essential organs
  - Stomach and gut shut down (butterflies in tummy)
- Blood shunted to muscles and vital organs
  - Ready for action

Recognising symptoms of stress is important. The feeling of not being in control can make symptoms worse and lead to secondary effects such as fatigue, pain, poor concentration, sleep problems and stomach problems. Prolonged stress has a marked affect on your body:
- Thoughts locked
  - Feel trapped
- Hard to focus
  - May cause headaches
- Dry mouth
  - Lump in throat
  - Choking feeling
- Breathing faster
  - Too much oxygen
  - Light-headed and faint
- Stomach and gut shut down
  - Diarrhoea
  - Pain, feeling sick
- Main muscles tense up
  - Feel sweaty – hot, cold or clammy
  - Aches and pains
  - Restless, exhausted
Heart beats faster
  • Frightening feeling
  • Think something is wrong

Blood supply shuts down
  • Feet and hands
    - Cold
    - Clammy
    - Cramps
    - Aches
    - Fists clench

Difficulties arise when people experience these ‘secondary symptoms’. Some individuals can feel their condition is worsening.

Current medication may be increased

Further investigations show that ‘nothing is wrong’

People may start thinking their symptoms are ‘all in their mind’

You may worry that you have a serious undiagnosed and medically unexplained condition, for which there is no treatment

Knowing how stress works can help you manage the stressful situation by breaking down the components. Using relaxation can help control and reduce the symptoms of stress.
Sleep Management

Studies show that 20% of Myalgic Encephalomyelitis - Chronic Fatigue Syndrome patients may not have the syndrome but rather a treatable sleep problem. The recommended amount of sleep for Myalgic Encephalomyelitis - Chronic Fatigue Syndrome patients is 8 – 9 hours. Ongoing sleep disruption can begin to affect immunity. A poor sleep pattern may be a sign of excessive worry and/or distress. It may also be symptomatic of unhelpful habits that can, with a little effort, be changed in favour of more beneficial ones. An altered wake-sleep cycle can lead to a downward spiral into depression.

The Altered Wake-Sleep Cycle

1. Disturbed and un-refreshing sleep
   Excessive dreaming
   Wake early

2. Fatigue, exhaustion symptoms – missing restorative sleep stages

3. Psychological distress

4. High emotional and physiological arousal – can lead to a decreased tolerance to pain

5. Excessive negative and depressive thoughts

Waking early and exhausted after a disturbed night’s sleep (1 and 2) makes it difficult to move through the next day.

This can be quite distressing to many people, and studies have shown that the ‘fight or flight’ stress response is more active (3).

This means we find it difficult to cope and our reactions to pressures of the day can be over-emotional (4).

This state can lead to excessive build up of arousal in the brain caused by negative and depressive thinking (5) and recent studies have shown that the brain, when asleep, discharged built up emotional stress through the dreaming process. This is why the brain wakes the body up early – exhausted by its attempts to discharge the arousal and can do no more. Waking up exhausted sets up the cycle for the next day.

This is why many people with depression report waking up early, feeling exhausted and lacking in motivation.
Restoring a healthy wake-sleep cycle

Practicing some of the techniques below can help wake-sleep cycle

1. becoming more active (to help cope with fatigue)
2. practising relaxation techniques (to cope with stress)
3. finding distractions from worries and taking part in pleasurable activities
4. spending some time during the day, not the evening, to jot down worries, to consider solutions and actually taking steps towards resolving worries
5. reviewing what went well at the end of the day
6. achievement
7. going to bed at the same time each night – ideally when tired
8. setting your alarm to get up at the same time each morning even if you are still tired – turn the clock away from you before you go to sleep
9. avoiding at bedtime
   - frustrating conversation or quarrel
   - having caffeine based drinks in the evening
   - reading an exciting or work related book
   - watching TV or eating in bed
   - using a computer just before bedtime
   - worrying when you are in bed
   - hand – eye coordination activities such as jigsaws/crosswords to help slow the brain down
10. associating the bedroom with sleep
    - removing the television from the room
    - making sure that the room is dark and the bed is comfortable and cool
11. Melatonin is a chemical which encourages sleep and regulates your body clock. This chemical is stimulated by the dark, so keep your room dark. This can be helped with blackout blinds. Avoid putting on lights if you waken during the night.
12. do not go to bed hungry or on a full stomach
13. use your diary planner to help log your sleep pattern
14. Have a pen and paper by the bed (so if you suddenly remember something you can write it down to prevent worrying about forgetting the task).

Sleep patterns are based on:

- habit
- sleep association

If you can not get to sleep after 30 minutes, get up, keep warm and do something calming, soothing or even boring!!!!!

It is important to avoid napping during the day as this will affect the sleep pattern at night time. Changes to sleep pattern can take 3 weeks to show benefit so persistence is important.

Night sedation is not recommended, changes to sleep hygiene using the above principles will benefit sleep pattern more.
Getting active

There are many benefits to starting to get active. An inactive lifestyle can eventually lead to:

- Weak muscles
- Poor posture
- Stiffness/decrease flexibility
- Fatigue
- Lack of stamina
- Increased blood pressure
- Weight gain
- Osteoporosis
- Anxiety
- Stress
- Poor sleeping patterns
- Depression
- Aches and pains
- Increased sensitivity to pain

Being inactive long term can be a vicious cycle of events.
Inactivity can lead to a feeling of lethargy.

Begining to get active can be daunting especially as exercise can make you feel tired for a few days following. How to begin to get active will be discussed at your physiotherapy treatment sessions to ensure the exercise level is appropriate according to your symptoms.
EXERCISE

There are 3 types of exercise which will help improve posture, balance and coordination.

❖ Strength
  • Making your muscles stronger
  • Reduce strain on joints

❖ Stamina
  • More activities can be done
  • More energy

❖ Flexibility

When exercising, decisions will need to be made about

  Frequency – how often per week
  Intensity – how hard to exercise
  Time – how long to exercise
  Type of exercise – what form of exercise
  Adherence

Starting with smaller sessions of exercise and increasing the time will be more beneficial. To start exercising your baseline must be found. Start with something you know you can achieve e.g. a 10 minute walk. If your body is sore or you feel exhausted during the exercise then your body is telling you that you have reached your limit. You may feel some discomfort after exercising but this is normal and should resolve within 24 hours.
Making changes

Changes within our life occur at some point. Most people go through life changing different aspects of their lives. When changes are made there are different stages to work through before a change is made.

1. Not thinking about change
2. Thinking about change
   • Weigh up the pros and cons
   • Movement forwards beyond this stage is due to lack of confidence
3. Preparing to change
   • Making plans
4. Taking action
   • Decision on what or how to make changes taken and embarked on
5. Relapse
   • Relapse happens from time to time
   • Start afresh
6. Maintaining change
   • Feel good regarding changes made and feel differences in life
7. New habit established fully
   • Relapse may happen occasionally
   • Less likely to happen and easier to get back on the bandwagon

To make a change you could rate how important it is for you to make a change on a scale of 0 – 10. Alternatively you could make a pros and cons chart.
**Goal Setting**

Short Term Goals: help achieve short term goals

Long Term Goals: should be really important to you

**Make and action plan**

1. Decide on the goal you want to achieve in a time frame
2. Break down into tasks and steps (one per week)
3. Must be achievable and fit into a schedule
4. Be specific about what you will do, how often, how much and when

<table>
<thead>
<tr>
<th>Long Term</th>
<th>Short Term</th>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get more active</td>
<td>Exercise 3 times per week</td>
<td></td>
</tr>
<tr>
<td>Feel more refreshed after nights sleep in 6 months</td>
<td>Relax more</td>
<td>Practice relaxation technique daily</td>
</tr>
<tr>
<td>Deal with worries</td>
<td>Make a list of worries and sort through them</td>
<td></td>
</tr>
<tr>
<td>Develop a routine for bed</td>
<td>Go to bed and get up at same time</td>
<td></td>
</tr>
</tbody>
</table>

**My Goals**

**Long Term Goal**


**Short Term Goal**

1. 
2. 
3. 
4. 
5.

**Action Plan**

1. 
2. 
3. 
4. 
5. 

Myalgic Encephalomyelitis - Chronic Fatigue Syndrome
Pacing

Pacing is about balancing mental, emotional and physical activity with periods of rest to gradually increase your level of activity. Pacing will enhance our energy levels and can bring about improvements in the way we feel. Effective pacing will allow you to undertake activities without increasing your symptoms. Every 90 minutes our bodies settle into a relaxed state. Ignoring this rhythm can lead to accumulation of stress or decreased energy. Even when we follow our natural rhythms, energy levels can vary at times, resting when you feel fatigued seems like the best option but it becomes harder to regain previous activity levels. This can lead into the “Boom or Bust Cycle”.

- Loss of physical/psychological fitness
- Rest/doing nothing

- Doing too much (but not as much as before)
- Fatigue/Low mood/Anxiety symptoms

1. On a good day, there is tendency to take advantage and overdo things by trying to catch up on activities.
2. Leads to feelings of exhaustion and a big dip in how ability to do anything on the next or following days.
3. As we have periods where we do little or nothing.
4. Our physical and mental ability begins to decline.

Prolonged boom/bust cycle can lead to lethargy and can result in feeling bored and discouraged with carrying out activities.
- Staying in bed
- Procrastinating
- Becoming isolated from friends

Pacing involved working out what you can tolerate on so-so days and sticking to that level even on good days to avoid the boom/bust cycle. Finding your baseline is important. This can be done by:
- Noticing the natural fluctuations in energy levels throughout the day
- Noticing the effect of physical, mental and emotional activity has on your body
- Listening to your body

Keeping an activity diary can help with finding your baseline. An important part of pacing is regular rest and relaxation. Anything that stimulates your brain either physically or mentally can be called an activity e.g. television, crossword, making a cup of tea or getting washed and dressed.
How to Pace

- Develop a normal sleeping pattern
  - Go to bed and get up at the same time
- Control your emotions
- Plan your activity level based on a so-so day
  - Not the best or the worst day
- Alternate rest and activity throughout the day
  - Low and medium level activities spread throughout the day
- Break down high energy activities into achievable chunks
- Consistent patterns of activity
  - Ensure some flexibility
- Include pleasurable activities
- Less activities in the evening

Time management goes hand in hand with pacing. Some days it can feel that you are busy with nothing productive done or rushing to get everything finished.
EXAMPLES OF POOR PACING

Monday:
- Got up around 10 felt really good, got washed and dressed and made breakfast.
  Decided to clean downstairs.
- Made lunch and watch TV for an hour.
- Cleaned upstairs and went shopping.
- Made dinner, watched TV and went to bed at 10pm.

Tuesday:
- Got up around 12 really tired from yesterday, got washed and dressed then met a friend for lunch.
- Came home early was meant to stay out all afternoon. Went for a sleep.
- Woke up around 5. Made dinner then went to bed at 8pm.
- Eyes relaxed

Wednesday:
- Woke up around 12 still feeling tired but little bit more energy.
  Got washed and dressed then made breakfast.
- Watched TV then went for 10 minute walk
- Made dinner, read a book then went to bed at 10pm.

Thursday:
- Got up at 8am and made breakfast. Feeling much better, got washed and dressed.
- Went for an hour walk
- Made lunch for friends visiting.
- Went clothes shopping
- Went to parents for dinner then went out for a night out with friends. Went to bed at 1am.

Friday:
- Woke up around 11am. Bit tired but got loads to do today.
  Got washed and dressed then made breakfast.
- Watched TV for an hour then made lunch.
- Helped friend move house.
- Had late night helping moving boxes. Went to bed at 11pm

Saturday:
- Woke up around 2pm and made breakfast. Watched TV all afternoon.

Sunday:
- Got up around 12 still really tired. Got washed and dressed then met a friend for lunch.
- Went for a sleep when I got home then read my book for an hour.
- Made dinner and went to bed at 9pm.
EXAMPLES OF GOOD PACING

Monday:
- Got up around 9am and made breakfast.
- Rested for an hour then got washed and dressed.
- Rested for an hour then made lunch.
- Went for half hour walk.
- Cleaned the living room then rested for an hour.
- I made dinner then watched TV.
- Went to bed at 10pm.

Tuesday:
- Got up around 9am and made breakfast.
- Rested for an hour then got washed and dressed.
- Rested for an hour then met friend for lunch.
- Did relaxation for an hour with music.
- Cleaned the kitchen then rested for an hour.
- I made dinner then read a book.
- Went to bed at 10pm.
- Ordered takeaway too tired to make dinner. Cancelled plans with friends. Went to bed at 8pm.

Wednesday:
- Got up around 9am and made breakfast.
- Rested for an hour then got washed and dressed.
- Rested for an hour then made lunch.
- Did relaxation for an hour then went for half hour walk.
- Cleaned my bedroom then rested for an hour.
- I made dinner then watched TV.
- Went to bed at 10pm.

Thursday:
- Got up around 9am and made breakfast.
- Rested for an hour then got washed and dressed.
- Rested for an hour then made lunch.
- Rested all afternoon
- Went to parents for dinner.
- Met friends for night out then went to bed at midnight.
Friday:
- Got up around 10am and made breakfast.
- Rested for an hour then got washed and dressed.
- Watched TV for an hour then made lunch.
- Did relaxation for an hour then went for half hour walk.
- Cleaned the bathroom then rested for an hour.
- I made dinner then read a book.
- Went to bed at 10pm.

Saturday:
- Got up around 9am and made breakfast.
- Rested for an hour then got washed and dressed.
- Rested for half an hour then went shopping with friends.
- Rested for an hour
- I made dinner then watched TV.
- Went to bed at 9pm.

Sunday:
- Got up around 9am and made breakfast.
- Rested for an hour then got washed and dressed.
- Rested for an hour then went to parents for lunch.
- Did relaxation for an hour.
- Cleaned hallway and small bedroom then rested for an hour.
- I made dinner then watched TV.
- Went to bed at 10pm.

How to apply good pacing is dependant upon the activities you are able to do and the goals you want to achieve. Some activities will need to be prioritised on a daily basis but in general all activities will be spread out over the week to ensure good pacing. A mock plan of your week will be drawn up with your physiotherapist to assist you with your pacing.
Additional diaries can be obtained from your physiotherapist. Discussion around how to plan and prioritise your day will be discussed at your physiotherapy session.
PREVENTING AND MINIMISING SETBACKS

Setbacks in life can occur through a variety of reasons. These setbacks can be managed by having a contingency plan and crisis plan and being prepared for all eventualities.

When you are on track:

- You have a clear idea of where you are going (goal)
- You have a clear idea of your immediate action plans

When you feel like you are not coping as well as you would like or your routine begins to slip your contingency plan should come into force to help you stay on track. You therefore need to recognise the signs that you are not staying on track. Below is an example of a contingency plan.

**What are the key features of a typical day for you when you are “on track” towards recovery?**

- Get up at 9am everyday
- Exercise for 30 minutes daily
- Complete some household chores
- Do a social activity everyday
- Relax at some point during the day

**Know The Triggers And Early Warning Signs**

**What are my triggers or early warning signs that show me I’m beginning to go “off track”?**

- Low mood
- Staying in bed
- Not eating well
- Not returning calls

**Enlist Support And Tell Supporter How They Can Help**

**Who else would notice me moving “off track”?**

- Partner
- Friends

**Take Action**

**What has helped in the past or can help in the future to get me back “on track”?**

- Friends making me come out
- Partner helping with household chores

If you do not notice that your routine is slipping or you have relapsed back into your old routine, then the crisis plan should be used to stop things getting worse and help you get back on track to achieving your goals. The crisis plan should look at:

- What stops you sinking deeper?
- What would help you get out sooner?
- Who could help you get out?
- What are the signs of things beginning to improve?
Below is an example of a crisis plan.

### Knowing When You Are In Crisis

How do I and others know when I’m in crisis – what are the signs?
- Staying in bed
- Not contacting people
- Feeling isolated

### Enlisting Automatic Support (Before You Need It)

Who can help? (Doctor, Partner, Friend)
Who can I or others contact on my behalf?
- List of names and phone numbers to contact

### Stopping Things Getting Worse

What can help prevent further set-back? Start practising relaxation techniques.
What am I already doing that is stopping things becoming worse? Looking at my crisis plan
What else can I or others do to stabilise things? Remind me to do more of what works best

### Do I Need Treatment?

Have I to go anywhere?
- GP appointment/Consultant

### Recognising The First Small Signs Of Recovery

How can I or others know that I am beginning to recover?
- Starting to do some gentle activities
- Contacting friends

### Taking Action (First Steps)

What can I or others do as a first step towards recovery?
- Re-set baseline activities
- Getting into a routine again (pacing and planning)

### Knowing What To Do Next

What has helped in the past or what can help in the future?
- Relaxation
- Pacing

### Back On Track

How do people who help me know when there is no longer any need to use this plan?
- When I am back to my normal daily routine
To make your own contingency and crisis plans work for you, you need to sit down and plan how you can overcome the problems. This can be done by looking for solutions to the problems that you are facing.

The problem needs to be identified.

- List as many ways round it as you can think of.
  - Sit down with a piece of paper and give yourself a good 20 minutes to think of as many ideas as you can, even if they sound a bit far fetched
  - Write all your ideas down
- Pick one idea off the list
  - Chose the one that you feel is the best option and put it into operation
- See how it goes
  - If it works then this should be added to your contingency and crisis plans for the future
  - If not
    - Pick another idea off the list
    - Ask someone else for ideas
- If the solution did not work, accept that you may not be able to solve it right away and come back to it at a later date.

Keeping a note of the ideas that work best for you to get back on track will assist you in the future if you need to use the contingency and crisis plans again.

**Summary**

Recovery from Chronic Fatigue Syndrome is dependant upon the severity of the patients’ symptoms. Every patient’s needs are different and will therefore need to be tailored sessions from the physiotherapist to achieve change within their condition.

The information within this book is not exhaustive of the information that can be used to treat some of the symptoms of your condition.

**Useful websites**

www.livinglifetothefull.com

A general self help site offering advice on a wide range of issues, helping you to understand your behaviour and thoughts. Offers helps on healthy living, better sleep and relaxation.

www.meassociation.org.uk/

www.sleepfoundation.org

www.nhsinform.co.uk/health-library/articles/c/chronic-fatigue-syndrome/symptoms.aspx
CONFIDENTIALITY AND THE USE OF PATIENT INFORMATION

For the purpose of your present and future medical treatment, we will record details of your care. Some use may be made of this information for research purposes and to help in the planning of health services for the future. Some information will be processed on a computer. Information about your care and treatment may also be viewed by inspectors authorised by the Scottish Government. At all times great care will be taken to ensure that your information is kept confidential.

The “Data Protection Act 1998” gives you the right of access to any personal information which NHS Lanarkshire hold about you either in manual records or on its computers. If you wish to apply for access to your data, or if you would like more information about your rights under the Act you should, in the first instance, contact the Health Records Manager at the hospital.

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If you need this information in another language or format, please contact the NHS Lanarkshire General Enquiry Line on 08453 130 130 or e-mail info2@lanarkshire.scot.nhs.uk