Patient information on CFS/ME and self management

What is Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis?

The condition has been called by a variety of names including Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME) and Post-Viral Fatigue Syndrome (PVFS). It is classified by the WHO (World Health Organisation) as a neurological condition. However, it is a diagnosis that does not fit under one specific medical speciality and a variety of different medical specialists provide services in different areas of the country. We use CFS/ME which has been the most widely recognised and used in the Chief Medical Officer’s report and National Institute for Clinical Excellence (NICE).

The main symptom of CFS/ME is a feeling of unusual and excessive tiredness that is characteristically made much worse after any activity. The fatigue is usually both physical and mental. The fatigue would be of new onset rather than life long and impacts on your life to the extent that you have to cut down significantly on what you do day to day. It is important that other medical conditions that can cause significant fatigue are excluded before the diagnosis of CFS/ME is made.

CFS/ME is different from a more short-lived fatigue that may occur after many common illnesses especially viral infections. By definition, the diagnosis of CFS/ME is only made after you have had the symptoms for at least 6 months.

♦ Physical Fatigue

The physical fatigue lasts longer and is more severe than normal - ‘I feel drained’, ‘it’s like dragging a dead body around’, ‘I’m exhausted, as if I’d run a marathon’ are typical comments. It often has a fluctuating pattern, which is made worse by activity and is not made substantially better by rest.

♦ Mental Fatigue

The mental fatigue leads to difficulty in concentrating or muddled thinking. Slips of the tongue and difficulty finding the correct words may cause considerable embarrassment. Some sufferers have difficulty remembering simple things or doing more than one task at a time.

Both types of fatigue are at a level where they stop you doing normal everyday activities. There may be good and bad days but characteristically any undue exertion results in a significant period of fatigue / worsening of symptoms (pay back).

♦ Other Symptoms

Most people with CFS/ME have disturbance of sleep. People usually sleep for longer than usual in the early illness, but sleep often becomes difficult and broken as the condition continues, Un-refreshing sleep is characteristic.
People who have CFS/ME may have other symptoms in other areas of the body. Common symptoms are aching in the muscles or joints, which become tender to touch, muscle twitching and discomfort at night are not unusual. Recurrent sore throats, feeling hot and cold, sweats, mild fever (usually less than 38.5°C) and painful neck glands are common. Headaches, dizziness and ‘fuzziness’ are also common and there may be increased sensitivity to loud noises or bright lights. Some people have visual disturbances with blurred vision at times, although their eyes appear normal, when their vision is tested by an optometrist (optician). Many people also suffer from irritable bowel syndrome such as abdominal bloating, abdominal pains and intermittent diarrhoea and constipation.

Feeling demoralised, frustrated, depressed or irritable can sometimes be the consequence of the illness. Sufferers often feel isolated because, although debilitated, they look outwardly well and worry that other people may not understand.

**Who gets CFS/ME?**

Anyone of any age can get CFS/ME. Research shows a more even spread through all social groups. In the Service we see about twice as many women as men.

The exact number of people in this country who have CFS/ME is not known but estimates have suggested that 40 in 10,000 may be affected, for example this would mean about 3000 sufferers in Leeds.

**What Causes CFS/ME?**

The exact cause is not known. This is not unusual in medicine e.g. no one knows what is the exact cause of migraine or multiple sclerosis. Many of the symptoms in CFS/ME suggest some upset in the function in the hypothalamus, which is part of the brain that is a controlling centre for sleep, autonomic nerves (nerves which govern the automatic functions of the body such as the pulse rate, bowel function, skin blood flow) and the endocrine system (pituitary, thyroid, adrenal glands). Current hypotheses about the cause of CFS/ME include:

- **Infection hypothesis**

When a person has a viral infection such as influenza, many of the symptoms are due to the immune reaction caused by the virus. This is the way the body recovers from a viral infection but during the immune reaction there is release of a number of powerful substances from the immune cells (called cytokines), which cause fever, myalgia and fatigue. The cytokines can act at various parts of the brain, especially the hypothalamus (which controls many of the body’s basic functions) that could account for the various symptoms such as sleep disturbances and autonomic imbalance. The hypothesis is that in some people the immune system continues to react even when the virus has gone and this produces CFS/ME. Investigations of the immune system in CFS/ME sufferers do show some abnormalities that reflect an overactive immune response, but these are not specific. It is important to understand that in CFS/ME there is no evidence that the immune system is underactive.
Autonomic changes

This theory suggests that there is an imbalance of a chemical substance called acetylcholine in the central nervous system that is triggered by a viral infection or chemical exposure (e.g. chemicals such as pesticides or the drugs used in the Gulf War to protect against nerve gas). The acetylcholine is a neurotransmitter and a relative deficiency has widespread effects, which could account for the neuropsychiatric symptoms in CFS/ME and hypothalamic disorder. However, recent trials of medication affecting the cholinergic system have not been shown to be effective.

There is some data suggesting that sufferers may have an increased genetic tendency to switch on genes associated with the stress or ‘fight or flight’ response and this may contribute to continuation of the symptoms.

Causes without clear supporting evidence

There are a great number of other hypothesis which have been suggested, but as to date, there is insufficient supporting evidence for many of these ideas. These include persistent infection including candida and various allergies. Many people in the UK suffer from various types of allergy and there is speculation that this may in some way predispose them to develop CFS/ME. It is not clear that this is indeed the case. However, patients with CFS/ME often develop intolerances and sensitivities to various food stuffs and chemicals which appear not to be true allergic reactions but nevertheless may contribute to the overall illness burden.

Depression/Anxiety

Because some of the symptoms in CFS/ME are similar to those of depression, some doctors have suggested that CFS/ME is depression in another form. Although some symptoms overlap, there are also clear differences in the pattern of symptoms of depression and CFS/ME. Nevertheless, CFS/ME, like many other chronic illnesses, may lead to depression. It is also true that fatigue is often a prominent symptom in depression so it is important that a diagnosis of depression is not missed in patients with fatigue, so that they are managed appropriately.

Many people also report significant anxiety or stress symptoms in this condition. Many people report stressful events at the outset of the illness and those may add to the loss of energy they experience. There are also many reasons why having CFS/ME can bring on anxiety / stress symptoms. When people have limited energy and/or concentration span, it becomes difficult to do simple tasks they managed easily before. They may start to worry about making mistakes in public because of mental fatigue. When you have had to stop doing something from fatigue for some time, such as work, socialising or even simple day to day tasks like shopping, it is easy to lose confidence and feel anxious about facing these tasks. Anxiety symptoms can affect your sleep or appetite and make it harder to get the rest and fuel you need to recover from the illness. If these symptoms escalate to the point of becoming an anxiety disorder, they will in themselves worsen the many symptoms of CFS/ME and need additional treatment.
A holistic view

It is increasingly recognised that CFS/ME is a condition which may have a number of different triggers or cauasion that leads to a common condition. The triggers can be physical (eg infection) or a combination with both physical and emotional stressors. Therefore, our view is that going down the physical vs psychological debate is unhelpful, as it is not possible to split ourselves down the middle and separate them out. It is more important to view the person holistically, recognizing that more than one factor may play a role in either precipitating the condition or equally importantly holding people back from recovery. For instance, an often-recognised scenario is of someone already under stress who develops a viral infection, which triggers physical changes seen in CFS/ME. This then can lead to further stress or a depressive reaction that may worsen many of the symptoms and can develop into a vicious circle.

How is CFS/ME diagnosed?

There is no specific test to tell whether you have CFS/ME. The diagnosis is largely dependent on the history of what the symptoms are, how they developed and on the exclusion of other conditions. Usually physical examination and routine blood tests are normal in CFS/ME. Therefore, we ask your GP to have carried out the standard set of blood tests to exclude other causes of fatigue before you are referred.

How is CFS/ME treated?

Unfortunately there is no specific single medical treatment for CFS/ME. Many different treatments have been suggested although few have been thoroughly tested. However, there is now good evidence for management strategies, which enable people to control and improve their fatigue levels by addressing how energy is used, and manage other factors which impact upon fatigue, as well as strategies to control debilitating symptoms. It also appears that these strategies can help to restore some of the imbalances in the body that contribute to the condition.

We believe in patients being central to the therapy process and doing as much as they can to help themselves.

What can I do to help myself?

You will find information from many people who say they have found a ‘cure’ for CFS/ME, but to date none of these treatments are been shown to be effective in reliable clinical trials. However you can improve your symptoms through managing your day to day activity. You know that when you try to do too much you suffer for it afterwards, and so you have to change the way you live your life. However it is important that you use grading activity to help you to do this, as under-activity or over-activity can prolong your condition.

What is grading activity?

Grading activity is a simple method of planning your activities and gradually increasing what you do. It is not an exercise programme! It aims to give you control over your problem with CFS/ME symptoms, rather than the fatigue controlling you.
Most people experience good days and bad days, people who suffer from CFS/ME often try to fit in things they didn’t do on the bad days into the good. This results in them feeling tired again and not being able to do anything - a vicious cycle of “BOOM AND SLUMP”- which involves using all your energy up as soon as you experience any reduction in fatigue, and then finding it difficult to build up further energy for anything else. Grading your activity should help you to stabilize the boom-slump cycle.

The following terms are often used in relation to CFS/ME::

**Grading Activity** This involves analyzing all the requirements of everyday activities (such physical, mental, social, environmental), establishing a baseline of the activity you currently can achieve, and building up your levels in realistic steps. Progress to the next step can only be made once the current level can be achieved repeatedly.

**Pacing** This term relates to the speed of a task, it is only one aspect of grading.

**Goal Setting** Writing specific goals is a way of describing each step of your programme, it is a technique that helps you to focus on your targets and recognize your achievements.

**Graded Exercise** This describes exercise programs that would not be part of your normal routine, in which you continually increase the amount of exercise you undertake.

**What are the effects of too much rest?**

Resting too much can cause changes in your muscles that make it harder to do anything. If you don’t use muscles they tire more easily and become more painful after only a small amount of activity. This can lead to avoidance of any strain, which further increases the risk of experiencing muscle fatigue and pain. This creates a vicious circle, and your body becomes de-conditioned.

Excessive rest may also mean that you are not achieving anything so you feel a failure compared with what you used to do. It may also mean you have more time on your hands to brood on your condition and so become frustrated and bored.

**Isn’t activity harmful?**

Grading activity is not about going jogging! In fact most people when they start grading activity have to cut down the amount that they are doing, because they were doing too much before. Grading activity does not mean pushing yourself beyond your limits. It aims to stop the boom-slump cycle and replace it with a gradual change in some of your activities.

**How do I start?**

It can be helpful to keep a fatigue diary, the aims of doing this are to provide a record of the severity and fluctuations in your fatigue, which you can look back on and identify any factors that tend to make the fatigue better or worse.
What next?

The next stage is to select maybe two goals that are important to you. Perhaps one related to work, for example to be able to read for 20 minutes, and one you find enjoyable, possibly going for a walk for half an hour. You then have to break these tasks down into parts which you can do - no task is so small that you can’t divide it into smaller ones. Tasks may be broken down by time or the amount of an activity that you do, for example you may go for a walk for 10 minutes or 100 yards. Set your starting point at a level that you can achieve regularly without increasing your fatigue. Remember if you are starting to feel it you have already gone too far!

Having selected some long-term goals set yourself some targets for the week that will help you towards your goals. Once you have achieved that target, which may take some time, set another one that is a gradual increase on the last step. Try this new level (e.g. walking for 15 minutes instead of 10 minutes), if you can manage this regularly without increasing your fatigue levels you can then repeat the process. If you find it does increase your fatigue levels then return to your previous level and try to find a smaller next step (e.g. walking for 11 minutes instead of 10 minutes). The rate at which you can increase your activity varies from person to person so don't be worried if you have to take very small steps to start with. You will be working on a range of targets across your daily routine, try to keep a balance between grading physical, mental, social and relaxation/pleasurable activities. Keep on repeating this until you have achieved your goal and then choose another one.

An example: If your goal was to go for walk for 30 minutes the first target could be getting yourself ready to leave the house. The second target may be walking for 5 minutes every day, then building up to 10 minutes each day, etc. until you achieve your goal.

You will have weeks when you slip back or feel you can’t manage anything. This is normal and you shouldn't be dispirited. When you feel better try for the last target that you achieved and then carry on as before.

What follows is a collection of tips on how to carry out Golden Rules of Grading.

How can activity be broken down?

There are different ways in which an activity can be broken down into smaller units. Assess which method suits any particular activity from the following list:

**Time**  Allocate a set period of time to the activity, for example 5 minutes, 15 minutes, etc., starting from the time period you can currently manage, and increasing the time when you are able to. It is ideal if you can set yourself a timed plan for each day to try to follow consistently, as this allows you to see that you have a balance of activity and rest over the whole day.

**Distance**  Set a distance to how far you will walk, swim etc., it may be useful to use markers, such as a lamppost, or local shop.

**Speed**  This is a combination of distance and time, for example walking further in the same time period or completing the same distance in a shorter time. This method of grading is not useful in CFS/ME, as it is better to take your time over an activity then trying to increase the speed at which you do it.
Strength This often relates to the need to carry weight, for example only carrying a couple of items of shopping in two bags to distribute the strength needed between both arms, and building up the amount of weight that can be taken.

Resistance This applies to activities where something is working against you (such as gravity), for example when you are vacuuming there is the friction from the carpet, or it is harder walking up a hill. It is therefore easier to do activities where there is less resistance.

Rest The breaks between activity can also be increased /decreased to grade the activity. Smaller, more frequent rests may increase the total amount of activity achieved in comparison to a long rest afterwards.

Complexity The more complex the task is the more difficult it is to achieve, so it may need to be performed one part at time. For example not trying to do 2 things at once, such as talking on the phone and writing a message at the same time.

Grading Activity Summary

- START WITH SIMPLE TASKS
- BREAK EACH TASK INTO SMALLER STEPS.
- PLAN YOUR TIME.
- IF YOU TRY TOO MUCH TOO QUICKLY YOU’LL BECOME FATIGUED.
- IT IS EASIER TO ACHIEVE SMALL STEPS FORWARD.
- MAKE ACTIVITIES INTERESTING - WORK, REST AND PLAY.
- DO ONE THING AT A TIME.
- MAKE SURE YOU HAVE REST AND RELAXATION PERIODS.
- GIVE IT A GO!

Useful Addresses

Leeds and West Yorkshire CFS/ME Service
Therapy Suite, 1st Floor
Newsam Centre
Seacroft Hospital
York Road LS14 6WB
Tel: (0113) 8556330/1/4

ME Association
4 Top Angel, Buckingham
MK18 1TH
www.meassociation.org.uk

Action For ME
Third Floor
Canningford House
38 Victoria Street
Bristol BS1 6BY
www.afme.org.uk

© Leeds & West Yorkshire CFS/ME Service
CFS/ME Service Referral Form

PATIENT NAME, ADDRESS, DOB AND NHS NUMBER | GP Surgery (Name, Phone number and Address)
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**Reason for referral / relevant history:**

**Duration of symptoms**

**How the symptoms affect the patient’s function**

**Examination Findings:**

**BMI :**

<table>
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<tr>
<th>Essential</th>
<th>Desirable</th>
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<tbody>
<tr>
<td>FBC , ESR/CRP</td>
<td>Ferritin/folate</td>
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<tr>
<td>U&amp;E’s, LFT’s, Ca+ PO4</td>
<td>Vitamin D</td>
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<td>Blood glucose</td>
<td>Creatine kinase</td>
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<td>TFT</td>
<td>Coeliac screen</td>
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<td>Coeliac screen, CK</td>
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<tr>
<td>Urine analysis</td>
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**We require results of the following tests carried out within the last 6 months and will not accept referrals where those listed as essential are missing.**

Results should be attached on a separate sheet(s).

Other Relevant Investigations – Please use separate sheets if necessary
Other information:  
(Please complete or attach summaries/reports of significant past medical history)

<table>
<thead>
<tr>
<th>Other physical problems and co-morbidity</th>
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<tr>
<td><em>(If relevant please copy the correspondence)</em></td>
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<th>Family History</th>
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<table>
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<tr>
<th>Mental health history</th>
<th>Current Diagnosis</th>
<th>Date of Diagnosis</th>
<th>Previous Diagnosis</th>
<th>From</th>
<th>To</th>
</tr>
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<tbody>
<tr>
<td><em>(If patient has a mental health history, please attach reports and/or other relevant documentation)</em></td>
<td>None</td>
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<td>None</td>
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<tr>
<td>Depression</td>
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Current Mental Health worker name and contact details:

Other relevant history, including therapies and treatments already received for CFS/ME

*Please attach printout of current medication.*

Other Relevant Information

If you have any questions about completing this referral, please contact us on 0113 8556330 or 8556361
### CFS/ME Home Rehabilitation Programme Referral Form

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>DOB:</th>
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<tr>
<td>Address:</td>
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<td>Tel no:</td>
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<th>GP Name:</th>
<th>Surgery:</th>
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<td>Tel no:</td>
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#### History

**Onset –** Symptoms not predating the fatigue (cf Fukuda criteria)

- [ ] Impaired memory/concentration
- [ ] Headache
- [ ] Pain in several joints without redness or swelling
- [ ] Sore throat
- [ ] Muscle pain
- [ ] Feeling ill after exertion/activity
- [ ] Tender lymph nodes
- [ ] Unrefreshing sleep
- [ ] Other significant symptoms

#### Past medical and psychiatric history / treatment

#### Current medication

#### Physical state

- Current level of function:  
  - [ ] Bed bound
  - [ ] House bound
- Pulse and blood pressure
- Has postural drop been checked for?
- Any other relevant problems (eg pressure sores, low weight):
Have other physical causes of fatigue been excluded?

Have other psychiatric conditions been excluded? (e.g. eating disorder, bipolar affective disorder, psychotic disorder, dementia)

Results of investigations and dates
(please ensure these have been completed before sending in the referral)

<table>
<thead>
<tr>
<th>Results</th>
<th>Date of last test</th>
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<tr>
<td>FBC</td>
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<td>ESR</td>
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<td>U&amp;E</td>
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<td>LFTs</td>
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<td>Calcium, phosphate</td>
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<td>random glucose</td>
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<td>thyroid function</td>
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<td>coeliac serology</td>
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<td>urinalysis</td>
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Any other investigations

Other professionals currently involved in the patient care
(eg district nurse, physiotherapist, rheumatologist, etc )

Any other information that may help us in making a meaningful assessment

By completing this referral, I understand that the assessment and management is undertaken on a shared care basis between the primary care team and Leeds & West Yorkshire CFS/ME Service.

GP Signature

Print name

Date

Thank you for the information. After discussion in the team, we will get back to you with our plans for patient assessment. If we take on the patient, a member of the team will be allocated as a key worker to discuss the care plans with you.