

Leeds & West Yorkshire CFS/ME Service

Managing CFS/ME in Primary Care

MANAGING CHRONIC FATIGUE SYNDROME / ME (CFS/ME) IN PRIMARY CARE

Introduction

This leaflet is designed to offer advice on the diagnosis and management of patients who are presenting with chronic fatigue within the primary care setting, allowing suitable local, long-term care and management of this chronic and disabling condition. This can be used in conjunction with a referral to the Leeds & West Yorkshire CFS/ME Service or as an alternative to it, especially if the symptoms are mild in nature.

Patient information section is written with patients in mind and can be used as a resource in the primary care setting.

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Diagnosis, Investigation and Prognosis

Diagnosis

The diagnosis of Chronic Fatigue Syndrome/ME is made when the onset, course and impact of fatigue is characteristic, and after exclusion of other conditions (physical and psychiatric) that may cause fatigue. The fatigue should be of new onset rather than life long, but the manner of onset may be acute (such as after a viral infection) or gradual over a few weeks or months. The diagnosis and management strategies are the same regardless of the method of onset.

Under the criteria for CFS/ME (Fukuda *et al*, 1994) the fatigue should have been persistent for at least six months before a diagnosis of CFS/ME can be made, but NICE guideline uses 4 months (Table 1).

TABLE 1: CRITERIA FOR DIAGNOSIS OF CFS/ME

Chronic Fatigue

New onset (not lifelong)

Lasting at least six months (NICE = 4 months)

Substantial functional impairment
(Occupational social or personal activities)
Not substantially alleviated by rest

**At least four of the following
for at least 6 months:**

Memory or concentration impairment
Sore throat
Tender lymph nodes
Muscle or multi-joint pain
Headaches
Unrefreshing sleep
Post-exertion malaise lasting >24 hrs

No medical illness explaining the symptoms

No diagnosis of:

Psychosis (schizophrenia, mania, or psychotic depression)
Eating disorder (anorexia nervosa or bulimia nervosa).
Dementia.
Alcohol or substance abuse, current or in the prev 2 years
Severe obesity (body mass index over 40)

Fukuda K, Strauss S, Hickie I, Sharpe M, Dobbins J, Komaroff A, (1994). The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Ann. Intern Med* 121: 953-9.

NICE Reference: Turnbull N, Shaw EJ, Baker R, Dunsdon S, Costin N, Britton G, Kuntze S and Norman R (2007). Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children. London: Royal College of General Practitioners. (NICE Guidance CG53)

Symptoms

- Core symptoms are physical and mental fatigue.
- The fatigue is characteristically worse after physical or mental exertion either immediately or as a delayed response.
- Cognitive dysfunction is often present and leads to poor concentration and poor short-term memory.
- Non-refreshing sleep is usual and sleep pattern may vary between too much and too little both within and between patients.
- Low-grade fever (less than 38°C) and tender (but normal or small) lymph nodes and recurrent sore throats are reported.
- Head aches and mood disturbance is common.

Other symptoms are usually present in varying degrees. These include muscle and joint pains, and features suggesting autonomic imbalance such as inappropriate sweating, feeling hot and cold, pallor, palpitations, feeling faint, syncope, irritable bowel syndrome, and urinary frequency. Sensory disturbance with intermittent paraesthesia, sensitivity to light, loud noise and smells, and dizziness may be seen. Many patients observe that they are sensitive to the effects of alcohol and caffeine, may have food intolerances and seem prone to develop adverse effects of medication.

Signs

Physical examination is characteristically normal and any abnormalities need careful assessment as possible clues for alternative diagnoses. Postural hypotension is sometimes reported especially in patients who are significantly affected. Fevers, significantly enlarged lymph nodes or any objective signs of joint disease are more likely to indicate other disease. Symptoms or signs that are not typical of CFS/ME (e.g., high-grade fever, weight loss, enlargement of liver, spleen or lymph nodes) should be investigated separately, as indicated clinically.

Investigations

There is no validated diagnostic test for CFS/ME and the purpose of laboratory investigation is to exclude other conditions that may cause fatigue.

Minimum recommended investigations

- FBC
- Inflammatory markers- CRP and ESR or PV
- U&E
- Calcium + phosphate
- LFT
- TFT
- Urinalysis for protein, blood and sugar
- Screening for Coeliac disease if indicated by symptoms
- Creatine kinase

Other investigations should be performed when indicated by the clinical history and examination.

Any abnormal results need to be investigated and/or treated before making a diagnosis of CFS/ME . Symptoms of fatigue may take a number of months to resolve once abnormalities have been corrected.

Differential medical diagnosis

Symptoms of fatigue and myalgia are common in many inflammatory disorders. They are often present in moderate or severe cardiac, respiratory, renal, hepatic or neurological diseases but the primary problem is usually obvious in such cases. Chronic infective diseases are uncommon. There would usually be some abnormalities in the routine investigations that would give some clues.

There is a clear overlap in the symptomatology of irritable bowel syndrome, multiple food intolerances, fibromyalgia and CFS/ME. There is no evidence to suggest that there is an allergic basis to CFS/ME.

Sleep apnoea needs to be considered and investigated if patients present with sleep disturbance suggestive of this condition.

Ferritin and folate ideally should be within normal range. For a female of childbearing age we recommend a ferritin of >50ng/ml as evidence shows that lower levels could have an impact on fatigue. It may take some time for a low ferritin and folate to produce changes to the haemoglobin.

Low Vitamin D can also produce severe fatigue and muscle pain. We recommend that the range is within the sufficient quotient. A low or slightly inadequate Vitamin D may still produce fatigue. It is particularly important to consider vitamin D deficiency in patients who are housebound or with little sunlight exposure.

Differential psychiatric diagnosis

At the point of diagnosis, it is important to exclude psychiatric disorders that can result in significant fatigue, as the treatment of these patients would be different. Psychotic disorders, eating disorders, dementia and substance misuse are exclusion criteria for making a diagnosis of CFS/ME. CFS/ME and depression are different conditions, but it is common for them to coexist. The precipitant to CFS/ME may also have triggered a depressive illness, or depression may be secondary to the chronic nature of the condition, such as adjustment difficulties, loss of job, loss of status, strain on relationships, etc. Some patients also develop significant anxiety symptoms secondary to or alongside CFS/ME.

Pointers to a depressive illness are anhedonia, diurnal mood variation unrelated to activity, irritability, hopelessness and suicidal ideation. As most patients gain weight with CFS/ME, weight loss without a physical cause make a depressive illness or eating disorder more likely. However, some patients with CFS/ME may lose a significant amount of weight from extreme exclusion diets. It is also worth bearing in mind that patients with co-existing depression which is only partially treated may also continue to experience fatigue.

Anxiety disorder is a common comorbidity in patients with CFS/ME, but also can be a differential diagnosis for the symptoms.

An experienced general practitioner should be able to make a diagnosis of CFS/ME in most cases. Specialist medical or psychiatric referral is only required if the diagnosis remains in doubt.

Prognosis

Studies looking at prognosis in CFS/ME have produced widely varying results so it is not possible to give accurate figures. This is probably because of variations in case definition and populations studied. It has been suggested that about 20% of CFS/ME sufferers make a full recovery, 60% make improvement and 20% continue with long term symptoms. A proportion of patients would recover sufficiently to a good level of occupational / social function, but may experience relapse triggered by a number of factors such as viral or bacterial infections or other illnesses and significant life stresses.

Unfavourable prognosis is associated with prolonged duration of symptoms, untreated co-morbid depression and anxiety and beliefs around the need for a purely physical treatment. Therefore, the sooner the explanations and advice is given the better the outlook.

Monitoring Outcome of therapy

There is a National Outcome Database based in Bristol which collates anonymous therapy outcome data from services across England. Leeds and West Yorkshire CFS/ME Service has participated in this project from the outset, enabling us to benchmark the outcome of our therapy, which has always been comparable or better on the number of outcome measures monitored.

Management of the Chronically Fatigued Patient:

Guidelines for the practitioner

It is important to foster therapeutic optimism in these patients, and encourage patients to understand that the symptoms of the condition may be controlled and thereby increase functioning and quality of life.

If patients believe that nothing can be done it becomes a self-fulfilling prophecy with little or no improvement with the passage of time alone. In addition, patients who feel there is little hope of recovery tend to become despondent and prone to depressive illness.

The practitioner can educate the patient on the self-management of the symptoms whilst validating the condition and offering the advice contained in the patient information leaflet.

Management Principles

Understanding / Education of the nature of CFS/ME

We find that if the GP can demonstrate why a diagnosis has been made (i.e. that other conditions have been excluded and the principle diagnostic criteria are met) then that patient will be more willing to accept that they have a chronic condition and will therefore start to engage in taking some responsibility in managing the effects of CFS/ME. Otherwise GPs are asked repeatedly to refer for second opinions, and being asked for 'medical cures'.

Teach the concept of management of symptoms to achieve improvement

Many patients do increase quality of life and increase levels of activity once management principles are applied, and it is gaining some control over the condition that can improve patient's experience of the symptoms. As a proportion of patients can return to their previous level of function, it is not inevitably a chronic illness, but many would learn to manage the condition to sustain a good or satisfactory quality of life and occupational / functional level and may need to see it as chronic disease management.

Facilitate self management with support

The attached information leaflet on CFS/ME should help patients to understand their condition and can be used by the GP to help guide the patient to stabilise and then gradually increase tolerance of activity through using grading strategies.

Educate regarding Rest and Deconditioning

In the initial phases, the patient may be unable to avoid using rest as a coping strategy. However, in the long term, prolonged rest increases the risk muscle de-conditioning, postural dizziness and loss of stamina. The patients should be encouraged to balance activity and rest and see that shorter, more frequent rests are more beneficial than prolonged periods of inactivity followed by bursts of activity. 'Rest before exhaustion'. Conversely, some patients consider sitting down as rest, when they continue to engage in demanding mental activity, and it is important that the rest is defined by restorative activity rather than merely stopping doing some activity.

Activity versus Exercise

The two evidence based therapies Cognitive Behavioural Therapy and Graded Exercise Therapy both use similar principles of establishing a sustainable baseline of physical/mental

activity and grade this up in step wise fashion at a sustainable pace. An advice 'to increase exercise' in an unsupervised setting is counterproductive as it often leads to a boom and crash energy pattern. Also patients who are spending valuable energy on exercise to the detriment of carrying out important daily activities of living may find normal functioning can actually reduce as a result. Psychologically it is important that patients are involved in normal routines and roles. Exercise, if an important activity for that patient in their life, can be graded in the same way as other activities.

Teach concepts of activity analysis and grading of activity

Patients should be encouraged to record their use of energy in a daily activity diary, they may benefit from rating their fatigue levels to indicate activities that may be causing 'pay-back' fatigue or to establish patterns of over or under activity.

The patient should then be shown and encouraged to follow the principles of grading which is **described in the attached information leaflet**. If the GP feels that they are unable to fully advise the patient regarding this principle, occupational therapists in general, are trained in the use of grading activity or the GP may consider referral to the Leeds and West Yorkshire CFS/ME Service.

Socialising and pleasurable activities are to be encouraged.

Often patients with CFS/ME tend to reduce social or pleasurable activities, partly to devote energy to tasks they may have neglected to do whilst resting. Many patients feel guilty being seen to be doing pleasurable things and will avoid going out for fear that they are labelled as being 'shirks' or 'frauds'.

However, the emotional and psychological benefits of pleasurable activities can out weigh the amount of energy consumed in doing them, and can motivate patients to an extent to actually find that they have more energy as a result of having some form of social life.

Finally - it isn't what you do it's the way that you do it!

Patients can pursue almost any task, as long as they grade (break down) the activity. However certain sports and competitive games would be difficult to grade.

This is an important factor for patients who have given up a lifestyle and feel that they are a victim to the condition, and being taught the grading principle to return to an activity they were previously avoiding allows the patient to feel in control of their life once again.

Pain Management for CFS/ME Sufferers

Individuals suffering from CFS/ME often experience pain, which is often generalised myalgia, arthralgia or headaches. Once other causes of their pain/headaches are excluded, reassurance that the pain is part of the CFS/ME, and that it does not signify any other illness and that the pain should respond to the same therapeutic advice appropriate for the fatigue, remains the main approach.

Some patients may be able to manage these symptoms using non-pharmacological strategies. Relaxation and complementary therapies such as massage, aromatherapy and reflexology may help. Some patients report benefit from use of TENS machines or acupuncture.

However, if analgesics are needed, they should be encouraged to try simple analgesics such as paracetamol or ibuprofen in the first instance. Codeine or other opioids may increase fatigue and encourage dependence.

For those with chronic musculo-skeletal pain or headache, a tricyclic antidepressant e.g. amitriptyline or nortriptyline, can be helpful. The sedative side effects of the former may also benefit those with sleep disturbance. It is best to start at a low dose (10 to 25 mg) and titrate upwards to maximum effect or dose limiting side effects. Benefit for pain relief is usually achieved at low doses of up to 50mg. In a proportion of patients, excessive sedation is experienced and a liquid preparation of amitriptyline may be needed to use doses below 10mg.

Neuralgic pains may be helped by gabapentin or pregabalin if tolerated.

Referral to a pain clinic should be considered for patients with severe chronic pain.

Antidepressants and other medication

In patients with moderate to severe depression or significant anxiety that is interfering with their function, it is important that they are treated adequately in their own right as they will further impact on the patient's difficulties. If an antidepressant is considered, it is important that patients understand that the medication is prescribed to help their mood, which in turn would help them manage their fatigue more effectively. Antidepressants are not effective in producing energy or remove fatigue on its own.

Non-sedative antidepressants, such as an SSRI could be tried in the first instance, introduced at a lower than usual dose and slowly increased to a therapeutic dose, as many patients are sensitive to side effects. However, paroxetine is rarely used within the SSRI class because of its withdrawal effects. Sedative antidepressants such as amitriptyline at antidepressant doses tend to worsen the daytime fatigue. Some patients benefit from mirtazapine without worsening their daytime fatigue especially at higher doses but weight gain may be a problem. It is important to consider gastric protection with Proton Pump Inhibitors, if a non-steroidal inflammatory drug is being used alongside SSRI's, as the latter can affect platelet function and increase the incidence of gastro-intestinal bleeds.

There are some patients who are particularly sensitive to medication side effects. Liquid form could be used in such patients, eg: Citalopram (40mg/ml) can be started at 2mg (one drop), or Fluoxetine (20mg/5ml) starting at 4mg (1ml). The dose then needs to be increased slowly in a stepwise manner and may take some weeks to reach a therapeutic dose. The patients need the usual advice about the antidepressant effect not becoming evident for at least two weeks after reaching therapeutic dose and the need to remain on the medication for at least 6 months after full response in order to reduce the chance of a relapse of the mood symptoms.

For those patients in whom musculoskeletal pain and early insomnia is a particular problem, and a low dose tricyclic eg amitriptyline or nortriptyline 10 to 25mg, is used, NICE guideline recommends that co-administration is initiated by specialist services. Recent MHRA guidance suggest there is a risk of QTc interval prolongation if Citalopram / Escitalopram are co-administered with tricyclic medication, and if there is a need for ongoing co-administration, ECG would be advised to check the impact on the QTc interval.

Referral and assessment process

Leeds & West Yorkshire CFS/ME Service

◆ Team Members

We are a multidisciplinary team with clinicians in liaison psychiatry, occupational therapy, physiotherapy, cognitive behaviour therapy, nursing and dietetics. We also have a sessional GP with a special interest in CFS/ME. There is a clinical team manager and clinical therapy lead, and the whole team is supported by administrative staff.

◆ Location

The service is based in the Therapy Suite, 1st Floor, Newsam Centre, Seacroft Hospital, Leeds.

◆ Opening times

The service operates between 9.00am and 5.00pm, and we try to be flexible as regards the times that can be offered for appointments. If patients need to rearrange an appointment they can contact our appointments service on 0113 8556361.

◆ Referrals into the outpatient service

We offer assessment and treatment to patients who broadly meet the criteria of CFS/ME according to Fukuda Criteria (see Part I). However, in accordance with the NICE Guidelines, patients with more than 4 months' history may be referred if it appears that their problems will be chronic.

We will require:

- ✓ a brief history of the fatigue symptoms
- ✓ previous medical and psychiatric history
- ✓ list of current medication
- ✓ results of required blood and urine tests carried out within the previous 6 months (see page 4 or referral form for required tests)
- ✓ results of any other relevant tests done to exclude other causes of fatigue
- ✓ If the patient has had other medical or psychiatric assessments prior to their referral it will be helpful to have details such as copy letters from those consultations.

If significant details are missing, we may have to return the referral to you asking for further information. A referral form is available to use to facilitate the referral process (appendix A). We also accept referrals by letter and ask that sufficient information is included to allow us to ensure that other diagnoses have been excluded.

We are happy to be contacted to discuss potential referrals, if there is some question about a patient's suitability for the service.

◆ Referrals for home based rehabilitation

This is available to patients within 30 miles of the service base and whose needs require this level of intervention. The referral would need to be on a specific home rehabilitation referral form (Appendix B). On receipt of the referral, we will start the initial assessment process by

asking the patient and carer to fill in a detailed self assessment form, to document their current difficulties and level of function.

Referral address for Outpatient and Home Treatment Service

Leeds and West Yorkshire CFS/ME Service

Therapy Suite, 1st Floor

Newsam Centre

Seacroft Hospital

York Road

Leeds, LS14 6WB

Telephone enquiries: 0113 8556330/1/4

◆ Initial assessment and management in the Outpatient and Home Treatment Service

The Leeds & West Yorkshire CFS/ME Service has three components:

- 1) Multi-disciplinary Home Rehabilitation Service
- 2) Biopsychosocial assessment and diagnosis led by Dr. Hiroko Akagi, Consultant Liaison Psychiatrist and Clinical Lead. There is also sessional input from a GP with a Special Interest in CFS/ME.
- 3) Therapy services led by D. Taylor, Clinical Therapy Lead, are provided by occupational therapists, nurse, dietician, CBT therapist or physiotherapist within individual or group therapy settings. We also have input from “experts by experience” in developing and delivering some interventions.

The initial triage assessment will be offered on an outpatient basis. Complex referrals may be seen initially by GPwSI or liaison psychiatrist. The patient may be asked to return for a further assessment, but a comprehensive letter with recommendations and formulation will always be supplied once the assessment stage is completed.

If the patient requires transport, it will need to be arranged locally for their first appointment. If they need to return for further appointments, these will be arranged through our service.

◆ Referrals for inpatient admission – Yorkshire Centre for Psychological Medicine

The in-patient element of the CFS/ME service is provided by the Yorkshire Centre for Psychological Medicine (YCPM) on Ward 40 at Leeds General Infirmary. This unit has facilities for inpatient assessment and rehabilitation of patients with severe CFS/ME. Some patients may be admitted there via our Outpatient or Home Treatment Services. The unit also takes direct referrals for patients from a wider area. Further details can be obtained from the ward manager, Russell Saxby, Clinical Team Manager, The Yorkshire Centre for Psychological Medicine, Ward 40, Leeds General Infirmary, Great George Street, Leeds, LS1 3EX.

Useful Books

Fighting Fatigue; a practical guide to managing the symptoms of CFS/ME
Pemberton S, Berry C (Eds) 2009, Hammersmith Press.

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 causation 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 a 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

Leeds & West Yorkshire CFS/ME Service

Therapy Suite
 Newsam Centre
 Seacroft Hospital
 York Road
 Leeds
 LS14 6WB
 Tel: 0113 8556330 or 8556361
 Fax: 0113 8556337

| PATIENT NAME, ADDRESS, DOB AND NHS NUMBER | GP Surgery (Name, Phone number and Address) |
|---|---|
| | |

Reason for referral / relevant history:

Duration of symptoms

How the symptoms affect the patient's function

Examination Findings:

BMI :

| Essential | Desirable |
|-----------------------|-----------------|
| FBC , ESR/CRP | Ferritin/folate |
| U&E's, LFT's, Ca+ PO4 | Vitamin D |
| Blood glucose | Creatine kinase |
| TFT | Coeliac screen |
| Coeliac screen, CK | |
| Urine analysis | |

**** 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)

| | | | | | |
|---|--|--------------------------|--|-------------|-----------|
| <p>Other physical problems and co-morbidity <i>(If relevant please copy the correspondence)</i></p> | | | | | |
| <p>Family History</p> | | | | | |
| <p>Mental health history <i>(If patient has a mental health history, please attach reports and/or other relevant documentation)</i></p> | <p>Current Diagnosis (Please tick)</p> | <p>Date of Diagnosis</p> | <p>Previous Diagnosis</p> | <p>From</p> | <p>To</p> |
| | <p>None <input type="checkbox"/> Depression <input type="checkbox"/> Psychosis <input type="checkbox"/> Bi-polar <input type="checkbox"/> Anxiety <input type="checkbox"/> Other: _____</p> | | <p>None <input type="checkbox"/> Depression <input type="checkbox"/> Psychosis <input type="checkbox"/> Bi-polar <input type="checkbox"/> Anxiety <input type="checkbox"/> Other: _____</p> | | |
| | <p>Current Mental Health worker name and contact details:</p> | | | | |
| <p>Other relevant history, including therapies and treatments already received for CFS/ME</p> | | | | | |
| <p><i>Please attach printout of current medication.</i></p> | | | | | |

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

Patient Name: _____ **DOB :** _____
Address : _____
Tel no: _____

GP Name : _____
Surgery : _____
Tel no: _____

History

Onset –

Symptoms not predating the fatigue (cf Fukuda criteria)

- | | | |
|--|---|---|
| <input type="checkbox"/> Impaired memory/concentration | <input type="checkbox"/> headache | <input type="checkbox"/> pain in several joints without redness |
| <input type="checkbox"/> sore throat | <input type="checkbox"/> muscle pain | or swelling |
| <input type="checkbox"/> tender lymph nodes | <input type="checkbox"/> unrefreshing sleep | <input type="checkbox"/> feeling ill after exertion/activity |

Any 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)

| Results | Date of last test |
|--------------------------|--------------------------|
| FBC | |
| ESR | |
| U&E | |
| LFTs | |
| Calcium, phosphate | |
| random glucose | |
| thyroid function | |
| coeliac serology | |
| urinalysis | |
| 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.