



**Cambridgeshire and  
Peterborough**  
NHS Foundation Trust

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

**A guide to the diagnosis and management of CFS/ME in  
primary care**



*Pride in our older people's and adult community services*

## Background

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) is recognised as a chronic illness. Early recognition with an authoritative, positive diagnosis is key to improving outcomes (working group to Chief Medical Officer (CMO) 2002). NICE guidance was published in 2007 and stated that CFS/ME should be recognised on clinical grounds alone. Primary healthcare professionals should be able to identify the characteristic features of CFS/ME. The purpose of this guide is to assist Clinicians in Primary Care to confidently diagnose and manage cases of CFS/ME and to decide when referral into specialist services would be of value to the patient.

## Diagnosis

Although we refer to CFS/ME as a 'diagnosis', it must be remembered that it is more accurately described as a criteria set. Some patients welcome this diagnosis as it can help them move on with their lives. However, patients can have more than one illness at a time and can develop new pathologies alongside current ones. Therefore, it is important that all new symptoms in patients with CFS/ME are investigated on merit.

The Centre for Disease Control (CDC) criteria is widely used for the diagnosis of CFS/ME (Fukuda et al 1994) and is used in conjunction with NICE guidance (2007). A diagnosis of CFS/ME should be considered when: -

- the patient has prolonged, debilitating and unexplained physical and mental fatigue
- the onset, course and impact of the fatigue is characteristic, and after exclusion of other physical and psychiatric conditions that may explain the patient's symptoms.
- the fatigue is new onset, rather than lifelong; it may emerge rapidly or gradually over a period of several weeks or months.
- the fatigue causes substantial functional impairment affecting occupational, social and personal activities, and is not alleviated by rest.
- the patient also experiences at least four of the following symptoms:
  - memory or concentration impairment
  - frequent sore throats – may include low grade fever
  - tender lymph nodes - not enlarged
  - muscle and/or multi-joint pain (without swelling or inflammation)
  - new onset headaches
  - unrefreshing sleep – may vary between insomnia and hypersomnia
  - post exertional malaise - either immediately or as a delayed response and lasting >24 hours

- symptoms have been persistent for at least 4 months in an adult and 3 months in a child or young person.
- there is no diagnosis of a severe psychiatric disorder (e.g. psychosis, eating disorder, dementia), alcohol or substance abuse, severe obesity (BMI >40) or other medical illness which could explain the symptoms.

When the diagnostic criteria of CFS/ME are not met it may be appropriate to make a diagnosis of '**Idiopathic Chronic Fatigue**'.

## Other Symptoms

In addition to the symptoms previously mentioned the patient may also experience the following symptoms: -

- Increased sensitivity to light, loud noises, smells, alcohol, caffeine, certain food and medication
- Light headedness, dizziness, shakiness
- Sensory disturbance with intermittent paraesthesia
- Palpitations
- Clumsiness, co-ordination problems
- Nausea / vomiting / gastrointestinal symptoms
- IBS symptoms
- Dysautonomia such as syncope, feeling faint, positional tachycardia and orthostatic intolerance
- Circulation problems such as cold hands and feet
- Bladder symptoms such as hypersensitivity and frequency
- Mood disturbance

## Investigations

Physical examination in CFS/ME is characteristically normal. Any abnormalities require careful assessment for other possible diagnoses. Signs or symptoms that are not typical of CFS/ME (e.g. fever, significantly enlarged lymph nodes / spleen / liver, signs of joint disease, weight loss) are likely to indicate other disease and should be investigated separately as indicated clinically. Postural hypotension is sometimes reported in patients with CFS/ME.

There is no diagnostic test for CFS/ME, however, the following tests are required as a minimum to exclude other conditions that may cause fatigue: -

- Blood tests: FBC, CRP, ESR, U&E, calcium, liver function tests, thyroid function tests, random blood glucose, creatinine, creatine kinase, ferritin, coeliac screen, protein electrophoresis, vitamin B12
- Urinalysis for protein, blood and glucose

## Differential Diagnoses and Other Associated Syndromes

Medical assessment is vital as fatigue is a ubiquitous symptom of disease. Patient's presenting with fatigue and myalgia may have other identifiable causes for their symptoms; these can include cardiovascular disease; malignancy; endocrine disorders; rheumatological disorders; respiratory, renal or hepatic conditions, chronic infection, neurological or inflammatory diseases. It is likely that routine investigations would reveal abnormalities in such cases. It is also important that other conditions, not assessed by routine blood tests, are also considered. Some of these are briefly discussed here: -

**Sleep disorders** such as sleep apnoea, restless legs syndrome and circadian sleep disorder may need to be considered if the patient presents with unrefreshing sleep, hyper-somnolence and an Epworth score of >11. These conditions can cause sleep disturbance and deprivation leading to excessive daytime sleepiness. Referral to a sleep centre may be required for confirmation and management

**Ferritin and folate** should be within the normal range. It is recommended that women of child bearing age should have a ferritin >50ng/ml before we consider CFS/ME as there is some evidence that fatigue is likely in this group when their ferritin drops below 50ng/ml.

**Low vitamin D** can produce severe fatigue and muscle pain; therefore, we recommend that vitamin D is within the normal range. Patients who are housebound and have little sunlight exposure may have vitamin D deficiency. For this reason, some patients with CFS/ME may require vitamin D supplementation and they should discuss this with their GP.

**Fibromyalgia Syndrome (FMS)** – FMS shares several symptoms with CFS. The main feature is of generalised widespread pain. Sufferers can complain of unrefreshing sleep, cognitive impairment as well as joint and muscle pain. It therefore can be a discrete syndrome or maybe part of a wide spectrum, FMS being at one end with CFS at the other. Evidence based medicine supports drug therapies such as Amitriptyline, Tramadol, Pregabalin and Duloxetine as well as non-drug therapies such as CBT, exercise (which may or may not be helpful to fatigue sufferers), relaxation and acupuncture. Where pain is predominant, referral to pain management teams would be preferred.

**Functional Disorders and Chronic Pain Disorders** – It can be difficult to differentiate between functional disorders and CFS/ME. Again, there is a commonality of symptoms. If a functional disorder or severe chronic pain disorder is suspected, refer to appropriate services.

**Joint Hypermobility and Ehler's Danlos Syndrome EDS**– Joint Hypermobility Syndrome and Ehler's Danlos Syndrome may present with muscle and joint pain and fatigue and can be misdiagnosed as CFS/ME.

**Irritable Bowel Syndrome and Coeliac Disease** – This is a commonly associated disorder in patients with CFS. The British Dietetic Association and NICE provide guidance for its management. Nocturnal diarrhoea could suggest inflammatory bowel disorder. Treatment for CFS should not commence until after the appropriate investigations have taken place. Coeliac disease should also be ruled out.

**Postural Orthostatic Tachycardia Syndrome (POTS)** – Studies are confirming autonomic dysfunction being strongly associated with CFS/ME. It can be confirmed in primary care when the pulse rate changes from seated to standing by >30 bpm, or, when it rises to >120 bpm. The fall in blood pressure may be delayed. It can also be confirmed by a tilt test which is available at specialist centres only and may need referral to cardiac services. Younger patients can demonstrate hypotension and recurrent syncope. Patients will need postural training, extra fluid intake and possibly increased salt intake.

**Dry Eye and Mouth Syndrome** – Some patient's volunteer these symptoms which could suggest Sjogren's Syndrome. This syndrome is also associated with fatigue and may demonstrate raised inflammatory markers. If this is confirmed the patients will require referral to a specialist service. In the absence of confirmation, they can be managed as CFS/ME

**Primary Psychiatric or Psychological Disorders** – 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 possible 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 this condition. Anxiety disorder is also a common comorbidity and may be a secondary or primary condition. Chronic depression, anxiety and obsessive-compulsive disorder

can present with exhaustion. Suspicion of any of these conditions should prompt referral for psychiatric assessment.

**Post-Traumatic Stress Disorder** – should be considered as it can directly cause fatigue or may predispose to fatigue symptoms.

**Primary Neurological Disorders** – should be considered where there is muscle wasting, tremor or abnormal muscle tone. Early Alzheimer's disease can present with fatigue. Refer to neurology if there are unusual neurological symptoms which are not typical of CFS/ME.

### **Prognosis**

It is not possible to accurately provide information regarding prognosis. Studies have produced widely varying results due to variations in case definitions and populations studied. It has been suggested that a minority of CFS/ME sufferers make a full recovery, a small proportion continue with long term symptoms, but a much larger proportion make improvements in their occupational and social functioning.

The sooner the patient is diagnosed, and advice provided, the better the outlook.

## **Management of the chronically fatigued patient Guidelines for the practitioner**

Patients with mild or recovering CFS/ME (e.g. able to manage fulltime work and capable of limited exercise such as walking) can be managed in a primary care setting.

It is important to foster therapeutic optimism in these patients and encourage them to understand that the symptoms of the condition may be controlled which in turn can improve functioning and quality of life.

If patients believe that nothing can be done it becomes a self-fulfilling prophecy with very little hope or improvement. Subsequently these patients are then at risk of despondency and become prone to depression.

The practitioner can validate the condition and offer support and advice as contained in the Cambridgeshire and Peterborough CFS/ME patient information leaflet.

For some patients, confirming the criteria and general advice on pacing can suffice.

## Education/understanding of CFS/ME

If a GP can demonstrate why a diagnosis has been made, that other conditions have been excluded, then that patient may be more willing to accept they have a chronic condition. This can potentially reduce the need some patients have in asking to be referred for second opinions and seeking 'medical cures'.

## Symptom management

Medication may be required for symptom management although patients may be sensitive to side effects and need lower than usual doses initially, gradually titrating upwards to achieve a therapeutic dose whilst limiting side effects.

**Sleep:** This may still be problematic despite good sleep hygiene. Some patients may benefit from low dose Amitriptyline (10-25mg) if tolerated. If excessive sedation is experienced, a liquid preparation of Amitriptyline may be needed for doses lower than 10mg. This can alleviate pain alongside its sedative properties. Melatonin can be of value in the <18 year old and >55 year old, especially if there is a shifting sleep pattern.

**Pain:** Patients should be reassured that the pain is part of CFS/ME and does not signify any other illness and that the pain should respond to the same therapeutic advice appropriate for the fatigue. Some patients may be able to manage their pain with non-pharmacological strategies such as relaxation and complementary therapies, for example massage, aromatherapy and reflexology. Other patients have reported benefit from TENS machines or acupuncture. If medication is required, paracetamol is a good baseline analgesic. Or, as in Fibromyalgia, patients may benefit from short term low dose tricyclics or gabapentinoids. Duloxetine can be useful for pain, sleep and mood disturbance. Referral to a pain clinic is recommended when there is severe chronic pain. It is important to consider gastric protection with proton pump inhibitors if a non-steroidal anti-inflammatory drug is being used alongside SSRI's, as the later can affect platelet function and increase the incidence of gastro-intestinal bleeds.

**POTS:** Increased fluid intake, support stockings and non-restricted salt diets are of value. Low dose betablockers of the cardio-selective type may help control tachycardia. Specialist centres may prescribe alpha 1 agonists such as midodrine or fludrocortisone.

**Mental Health Disorders:** Patients with co-morbid depression and/or anxiety should be treated adequately as these can negatively impact the patient's difficulties. Patients with CFS/ME are often particularly sensitive to the side effects of medication, therefore, SSRI's are best used at a lower than usual dose and slowly increased to a therapeutic dose. When depression or anxiety are severe, or there is

accompanying suicidal ideation, the GP would be advised to refer directly to psychiatric services.

**Important Note:** *MHRA guidance suggests that if a low dose tricyclic (e.g. amitriptyline or nortriptyline 10-25mg) is used alongside an SSRI (e.g. citalopram) there may be a risk of QTc interval prolongation. For this reason, co-administration of these two medicines should be initiated by specialist services and if there is a need for on-going co-administration, an ECG would be advised to check the impact this may have on the QTc interval.*

## **Self- management**

The key to managing CFS/ME is to recognise that alongside medical advice, careful and appropriate lifestyle and activity management strategies can help people feel more able to cope with their symptoms. These can enable people to control and improve their fatigue levels by addressing how energy is used, manage other factors which perpetuate fatigue and reduce the impact of debilitating symptoms.

Some people find they can use guided self-help information on their own whereas others require the support and expertise from the clinical specialists in the CFS/ME service to start the journey of recovery.

## **Referral to Specialist Services**

Referral to specialist services is appropriate if cases require confirmation of diagnosis, are complex and where there is a significant impact on quality of life.

Management of CFS/ME is predominantly based on a therapeutic approach with advice on self-management techniques, including

- Activity management (pacing and grading activity)
- Relaxation and rest
- Sleep and diet advice
- Exercise
- Support with employment
- Engagement in meaningful occupation
- Goal setting
- Coping with setbacks

## Cambridgeshire and Peterborough CFS/ME Service

### Team members

We are a small team of specialist nurses and occupational therapists with expertise in assessing and treating people with CFS/ME following NICE Guidelines and a collaborative evidence-based approach.

### Location

The team is based in Peterborough at Botolph Bridge Community Health Centre.

Initial assessments are mainly held in Peterborough at Botolph Bridge Health Centre, but therapy appointments are available across the county at Brookfields Hospital in Cambridge; Hinchingsbrooke Hospital, Doddington Hospital as well as Botolph Bridge Health Centre in Peterborough. We always discuss the best location for therapy with the individual.

Some patients who find it too exhausting or difficult to travel to appointments may be offered telephone consultations if this is appropriate.

### Referral Process

We offer assessment and treatment to patients who meet the criteria of CFS/ME according to the Fukuda Criteria outlined on page 1.

In order to process referrals appropriately and expeditiously we require the referral from the GP to be completed as per the referral guidelines, these in brief are-

- History of fatigue symptoms
- Symptom criteria checklist
- Previous medical and psychiatric history
- Results of required blood tests- carried out within previous 6 months
- List of current medication
- Signed disclaimer

**Important note- the CPFT service is a Nurse Specialist and Occupational Therapist led service and does not have a doctor.**

**If significant information is missing, we may have to return the referral to you asking for further information; this will lead to a delay in the patient being seen in the service.**

The link to our referral form can be found at <http://www.cpft.nhs.uk/services/chronic-fatigue-syndrome-and-myalgic-encephalomyelitis.htm>

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

## **Re-referrals**

Patients for whom we have already confirmed diagnosis and have had therapy with the team can contact us directly if they feel they require further input. In these cases, we will arrange a triage telephone consultation to discuss their needs and proceed as appropriate.

However, a GP is also welcome to re-refer a patient back to the team or a patient who has an existing diagnosis from another GP or specialist service. In these cases, you may wish to refer for further assessment or for therapy only and can indicate this on the referral form.

## **Assessment and Management in the CFS/ME Service (in brief)**

- 1. Triage process- referral form complete- criteria met- accept for Initial assessment.**
- 2. Patient sent questionnaire to complete- when returned- offered assessment appointment with clinician**
- 3. a) Initial assessment with specialist clinician- diagnosis confirmed- therapy discussed and offered- patient given choice of opting in to therapy.  
b) Initial assessment- diagnosis not confirmed- rationale discussed with patient.**
- 4. Assessment report written and sent to GP and patient with action points and recommendations.**
- 5. Patients who opt in for therapy will be offered individual sessions with one of the OT's for self-management advice and interventions.**

## **Monitoring Outcomes of Therapy**

The team use a variety of patient and therapist reported outcome measures with the aim of demonstrating the effectiveness of the interventions we provide. In particular, that patients report improvements in their ability to manage and cope with their condition and have the tools they need to continue for the future.

We discuss and compare measures with the patient and use them to report changes and outcomes to GP's.

Further information and all the self-help material used by the service can be found on our webpage.

<http://www.cpft.nhs.uk/services/chronic-fatigue-syndrome-and-myalgic-encephalomyelitis.htm>

## References and useful links

NICE guidance link - <https://www.nice.org.uk/guidance/cg53>

Leeds & West Yorkshire CFS/ME Service, 'Managing CFS/ME in primary care' booklet (2014)

British Association for Chronic Fatigue Syndrome / ME link - <https://www.bacme.info/>

ME/CFS/PVFS An Exploration of the Key Clinical Issues by Dr Charles Shepherd and Dr Abhijit Chaudhuri – (2018 edition)

'Fighting Fatigue' edited by Sue Pemberton and Catherine Berry

<http://www.cpft.nhs.uk/services/chronic-fatigue-syndrome-and-myalgic-encephalomyelitis.htm>

**As we wish to improve our service, we would appreciate your comments. We are happy to receive your feedback about this booklet, or for further information about our services, contact us at:**

CFS/ME Service

Location:

Botolph Bridge Health Centre

Sugar Way

Woodston

Peterborough PE2 9QB

Email: [cpm-tr.cfsme@nhs.net](mailto:cpm-tr.cfsme@nhs.net)

Postal address:

Administration Hub,

1, Commerce Rd,

Lynch Wood,

Peterborough.

PE2 6LR

Admin phone number:

03307 260077

Website:

<http://www.cpft.nhs.uk/services/chronic-fatigue-syndrome-and-myalgic-encephalomyelitis.htm>

---

*Leaflet published: April 2019*

## **Patient Advice and Liaison Service**

For information about CPFT services or to raise an issue, contact the Patient Advice and Liaison Service (PALS) on Freephone 0800 376 0775, or e-mail [pals@cpft.nhs.uk](mailto:pals@cpft.nhs.uk)

## **Out-of-hours service for CPFT mental health service users**

Please call **NHS 111** for health advice and support.

If you require this information in another format such as braille, large print or another language, please let us know.

---

CPFT supports the **HeadtoToe Charity** – visit [www.HeadToToeCharity.org](http://www.HeadToToeCharity.org) for details on how you can help

