

# Leeds and West Yorkshire ME/CFS Service

## Primary Care Guide to ME/CFS



# Contents

<b>Introduction</b>	<b>3</b>
<b>Diagnosis</b>	<b>4</b>
Fatigue	4
Post-Exertional Malaise	4
Additional symptoms	4
NICE diagnostic criteria	6
<b>Investigation</b>	<b>8</b>
<b>Management</b>	<b>10</b>
Education	10
Demands	11
Activity vs exercise	11
Pacing	11
Symptom management	12
Dysautonomia symptoms	12
Exercise	13
Diet	13
Mood	14
<b>Prognosis</b>	<b>14</b>
<b>Severe ME/CFS</b>	<b>15</b>
<b>Accessing Primary Care</b>	<b>16</b>
<b>Referral</b>	<b>17</b>
Leeds & West Yorkshire ME/CFS Service	17
Outpatient referrals	18
Referrals for Severely Affected Pathway	20
Access Issues	18
<b>Annual Review in Primary Care</b>	<b>21</b>
<b>Resources</b>	<b>22</b>
For Patients	22
For Clinicians	23

## Introduction

Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are interchangeable terms for the same condition and the current accepted name for the condition is ME/CFS.

ME/CFS is a condition which is defined based on a specific pattern of symptoms. There are currently no biological markers that can be reliably used for diagnostic purposes. It is recognised that ME/CFS is a heterogenous condition with associations with many other health conditions.

ME/CFS is an illness that can present with multiple symptoms affecting many different body systems and can have a very significant impact on a person's quality of life.

Making a confident diagnosis of ME/CFS is very important for the patient as it allows them to access appropriate information and support to help them manage their condition. It also allows the person and those around them to acknowledge, accept and adjust to having the illness as it will often require significant lifestyle changes to be made to manage the symptoms.

ME/CFS is not yet fully understood, however enough is known to provide a framework for making a diagnosis and distinguishing it from other conditions in which fatigue can be a primary feature. Research has made progress in helping us understand the disordered physiological process that generate the symptoms that occur and this knowledge can be used to help educate and inform patients about their condition and to guide them with implementing appropriate management strategies.

ME/CFS is a condition defined by symptoms which are caused by dysregulation in multiple dynamic systems in the body including the immune system, the autonomic nervous system, the endocrine system and the metabolic systems. All these systems interact with each other and when there is dysregulation or 'loss of balance' in these systems it results in a wide array of symptoms reflecting a lack of homeostasis at both a global and cellular level in the body.

More information about dysregulation is available from the document 'A guide to Dysregulation in ME/CFS' published on the BACME website [www.bacme.info](http://www.bacme.info)

## Diagnosis

As ME/CFS is a condition defined by a specific pattern of symptoms, detailed history taking will be required to make an accurate diagnosis. This may require several appointments over a period or a long appointment to fully evaluate all symptoms. The symptoms of ME/CFS overlap with other disorders, so other conditions need to have been considered and investigations may be required to rule out other causes for the symptoms or to identify contributing factors which may need to be addressed.

### **Fatigue**

This is the central feature of ME/CFS and the pattern of fatigue in response to activity and rest is important to elicit.

In ME/CFS the normal recovery systems of the body are not working properly so unlike the 'normal' tiredness everyone can feel, the fatigue of ME/CFS is often described as feeling very different. It is also important to distinguish between sleepiness and fatigue.

### **Post-Exertional Malaise**

In ME/CFS the key feature of the fatigue is that there is a clear activity related pattern. This is often referred to as Post-Exertional Malaise (PEM) or Post-Exertional Symptom Exacerbation (PESE). This is where there is a clear relationship between normal everyday activity levels causing a disproportionate escalation in fatigue which does not improve with rest and is slow to recover over several days. For some people the fatigue escalation can occur during or soon after stopping an activity but typically the significant escalation in fatigue is delayed and may occur hours or days after the activity which triggered it. This delayed escalation in fatigue is often accompanied by immune system mediated symptoms such as generalised flu-like malaise, tender lymph nodes, sore throats etc. Many patients also experience an escalation in other symptoms as well such as pain, headaches, brain fog, nausea, and sensory sensitivities.

Patients may not have recognised the delayed post-exertional pattern and may report a chaotic and fluctuating picture of better and worse days. Often what is happening is a 'Boom and Bust' cycle whereby they push themselves to do more on a better day then feel more ill the following few days and are forced to reduce their activity levels due to the escalation in symptoms. Prompting patients to keep an activity/fatigue diary can help them to identify if this PEM pattern is present.

### **Additional symptoms**

In addition to fatigue, patients with ME/CFS **will** have a number of other symptoms. It is important these symptoms are carefully evaluated to determine if further investigation is required to look for other possible causes of fatigue before attributing them to a diagnosis of ME/CFS. It is also important to ascertain that the symptoms are new since the onset of the fatigue illness and are not pre-existing conditions.

**Immune system:**

- tender lymph nodes
- recurrent sore throat
- recurrent flu-like symptoms or malaise
- new sensitivities to food, medications and/or chemicals

**Neurological/cognitive:**

- Poor concentration or “brain fog”
- Word finding difficulties
- Short-term memory difficulties
- Sensory hypersensitivity e.g., to noise and light

**Autonomic Nervous System Dysfunction (Dysautonomia):**

- Orthostatic Intolerance- symptoms which are worse in an upright position and improve with sitting/lying
- Dizziness/ feeling faint/ delayed postural hypotension
- Palpitations including Postural Orthostatic Tachycardia Syndrome (POTS)
- Urinary frequency/bladder dysfunction
- Nausea and irritable bowel symptoms
- Dyspnoea

**Neuroendocrine:**

- Difficulty regulating temperature
- Sweating episodes
- Intolerance of heat and/or cold

**Sleep:**

- Unrefreshing sleep
- Altered sleep rhythm – insomnia and/or hypersomnia

**Pain:**

- Headaches
- Muscles pains
- Joint pains

**Mood:**

- Anxiety
- Depression

## NICE diagnostic criteria

There have been many different groups that have formulated diagnostic criteria to be used for diagnosing ME/CFS. It is important to recognise that criteria used for research purposes may differ to that used in a clinical setting.

In the UK the National Institute for Health and Care Excellence issued a new Guideline on ME/CFS in 2021 and it includes the following diagnostic criteria:

### NICE Guideline on ME/CFS (2021)

When to suspect ME/CFS:

All of these symptoms should be present:

- **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- **Post-exertional malaise** after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days
  - is disproportionate to the activity
  - has a prolonged recovery time that may last hours, days, weeks or longer.
- **Unrefreshing sleep** or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia.
- **Cognitive difficulties** (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

## Diagnostic timescales

Time is an important diagnostic tool and if symptoms are progressive or rapidly changing that may indicate an underlying condition that requires further investigation and management. It can often take a long time before a confident diagnosis of ME/CFS can be made and that period of uncertainty can be very difficult for the person experiencing a wide array of debilitating symptoms with no apparent cause. It can therefore be helpful to recognise the symptoms early and consider having ME/CFS as a 'working diagnosis' while continuing to observe and investigate symptoms as appropriate. This will allow the patient to access appropriate advice on managing their symptoms which may be a protective factor in preventing deterioration.

To access the full NICE Guideline on ME/CFS please visit the NICE Guideline website: <https://www.nice.org.uk/guidance/ng206>

### **NICE Guideline on ME/CFS**

Suspect ME/CFS if:

- the person has had all of the persistent symptoms in box above for a minimum of:  
  
6 weeks in adults and  
  
4 weeks in children and young people **and**
- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels **and**
- symptoms are not explained by another condition.

Diagnose ME/CFS in children, young people and adults if:

- other causes of the symptoms have been confidently excluded and the symptoms in box above have persisted for over 3 months

## Investigation

With a potential symptom list so long it is easy to feel overwhelmed at the potential differential diagnoses that need to be considered. Careful history taking about each symptom can often be the only investigation required.

All children in whom you are considering a diagnosis of ME/CFS should be referred to a Paediatrician.

The minimum tests required when investigating a patient with suspected ME/CFS are:

**FBC**  
**U&E**  
**LFT**  
**TFT**  
**CRP**  
**Hba1c**

**Calcium**  
**Phosphate**  
**Ferritin** (aim for >50 in adults)  
**Coeliac Screen**  
**Creatine Kinase**  
**Urinalysis** for glucose, protein, blood

Other tests which may be warranted:

**ESR** (especially >50ys to exclude myeloma)  
**B12**  
**Folate**

**Vitamin D**  
**9am cortisol**  
**Serological tests for infection**

In ME/CFS the above investigations are expected to all be normal. If any abnormalities show up, they require evaluation and appropriate investigation before making a diagnosis of ME/CFS.

Other investigations and referrals need to be considered based on the patient's presenting symptoms. When referring patients to secondary care it can be helpful to mention that you are considering a diagnosis of ME/CFS so investigations can be planned with this in mind.

It is also important to manage the patients, and your own, expectations regarding what outcome you expect from referral and further investigation (e.g. to rule out a particular condition or to evaluate one specific aspect of their symptoms or abnormal results but not necessarily looking for an overall explanation or cure).

For people with existing ME/CFS it is important to remain vigilant for other conditions which may develop. If there is a significant change in the severity, nature or pattern



of symptoms consider revisiting investigations to look for other causes before presuming it is due to their ME/CFS illness.

**Common alternative or contributing conditions to consider looking for:**

- ➔ Sleep apnoea
- ➔ Primary neurological sleep disorders e.g. Hypersomnia (sleepiness rather than fatigue)
- ➔ Rheumatological disease e.g. psoriatic arthropathy, Rheumatoid Arthritis, Lupus
- ➔ Hypermobility Spectrum Disorder (consider this in patients with symptomatic joint hypermobility and multiple additional symptoms)
- ➔ Mental health conditions e.g. primary anxiety/depression, OCD, PTSD, eating disorders, dysthymia.
- ➔ Neurodiversity e.g. Autism Spectrum Disorder, ADHD
- ➔ Medication side effects e.g. opiates
- ➔ Primary endocrine disorders e.g. Suboptimally treated Thyroid disorders, Pituitary dysfunction following head injury

With regard to mood symptoms, it is important to exclude psychiatric disorders that can result in significant fatigue, as the treatment of these conditions would be different.

ME/CFS and depression are different conditions, but it is common for them to coexist. The precipitant to ME/CFS 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 ME/CFS.

Pointers to a depressive illness are anhedonia, diurnal mood variation unrelated to activity, loss of motivation, changes in appetite, low libido, low self-esteem, irritability, hopelessness, and suicidal ideation. 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 ME/CFS, but also can be a differential diagnosis for the symptoms. Severe anxiety states including PTSD can have a significant negative effect on ME/CFS symptoms and hence it is essential that appropriate treatment is sought for these problems through mental health services.

## **Management**

In primary care a consistent approach from an interested and supportive GP will be an invaluable part of the management plan.

The process of making a confident diagnosis of ME/CFS can take a long time especially if referrals and further investigations are required. This period of uncertainty is a very difficult time for the patient especially if they are off work or school or unable to manage their usual activities. During this time, they are vulnerable to the conflicting beliefs that exist about this condition and this can lead to them developing unhelpful behaviours and thoughts towards themselves, the illness and professionals involved in their care. Equally other people in their lives can have unhelpful attitudes towards their illness. Continuity of care from a supportive GP can help mitigate against some of these difficulties. This will make it easier for the patient to access appropriate help and be better prepared to put in place the behavioural strategies that are needed to manage this condition.

Because there are multiple dynamic systems contributing to the symptoms of ME/CFS there is not a direct treatment or strategy that will fix the problems. However, it is possible to identify factors which aggravate dysregulation and strategies which can help improve stability. The aim of management is to recognise which demands are causing symptom fluctuations and aim to manage those demands in a more controlled way along with looking at general factors like nutrition and sleep quality which will provide an environment for the body where healing and stability can occur. The pattern of symptoms and the body's response to different demands can vary over time so it will require a degree of experimentation to find strategies that help support recovery.

### **Education**

Patients will need to develop an understanding of their condition to learn how to manage it. Diary keeping can be a useful tool and can be applied to many symptoms including fatigue, sleep, diet etc.

Explaining how symptoms may arise can also help patients to understand their condition better and validate their experiences. Immune system dysfunction can give rise to symptoms of malaise, pain and fatigue. Autonomic System dysfunction can give rise to orthostatic or postural symptoms including fatigue, pain and palpitations. Autonomic problems have been found to be associated with reduced cerebral blood flow which is likely to be involved in the cognitive symptoms and brain fog that is experienced. The Autonomic System is also involved in regulating digestive processes including gut motility and blood sugar regulation so this can contribute to the gastrointestinal symptoms experienced and the symptom fluctuations that can occur in response to eating and fasting. Disruption to the normal sleep cycle can mean sleep is no longer restorative and hence why recovery after activity is compromised.

## **Demands**

Understanding the different physiological systems involved can help with recognising the wide array of demands on the body which can influence symptoms patterns.

There are everyday internal demands including physical activity, hunger, thirst, sleep, thinking, feeling, stress etc. There can be additional internal demands due to infection, illness, injury, or disease. There are also external demands which our bodies must respond to including the effect of gravity on the body, environmental temperature change and changes in air quality.

## **Activity vs exercise**

It is important for patients and clinicians to recognise that all types of activity are relevant when considering fatigue symptoms and management. Physical exercise is only one aspect of activity and cognitive activity, emotional activity and social activities all need to be considered.

## **Pacing**

Pacing is the basic principle that underpins ME/CFS management.

Complete rest will not make ME/CFS better – although patients will need to rest when their symptoms are severe, complete rest in the long-term will result in deconditioning and escalation of fatigue. Spending long periods of time lying down will result in the Autonomic Nervous System responses becoming more dysregulated in response to the gravity stress of being upright.

Equally, increasing exercise will not make ME/CFS better and can often trigger episodes of Post-Exertional Malaise which may lead to further dysregulation and cause an escalation in a patient's symptoms which can sometimes persist long-term.

Finding a careful balance between rest and activity throughout the day, every day is the basis of pacing. The concept of rest may need to be clarified to ensure patients are relaxing and resting both mind and body.

Patients will need encouragement to learn to rest frequently throughout the day, a helpful phrase is '**Rest before you are exhausted**'. When planning activities, it is helpful to break tasks down into short sections interspersed with rest periods, and, change between different types of activity. For example: do 10 minutes of housework followed by 10 minutes rest followed by 10 minutes of reading followed by a further rest period.

How pacing is done will depend on each individual patients' symptoms, their personal demands (e.g., work, care roles) and also the stage of their illness. In the early stages of the illness the primary aim is to achieve stability so the same level of activity can be performed every day without making symptoms worse. Once this has been achieved some patients can start to carefully grade up their activity. Some patients can also experience relapses and it is important they learn to recognise them and have strategies in place to manage them.

## Symptom management

It can be helpful to adopt a problem-solving approach to the multiple symptoms a patient may be struggling with. Consider asking them to prioritise which symptoms are causing the most distress or interference in daily life and see what creative solutions you can develop together.

Medication can be helpful for some of the symptoms that occur in ME/CFS. However, it is important that both the doctor and patient have realistic expectations about what the medication is aimed at rather than having the unrealistic expectation that one pill will cure all the problems.

Some patients with ME/CFS develop intolerance to multiple medications. It is therefore prudent to start any new treatment at the lowest possible dose and titrate up very slowly. Liquid medications are ideal as they often have less excipients and allow for very small dose changes. '**Start low and go slow**'. Make sure patients know to return for review so dose adjustments can be made and medication that is ineffective is stopped.

There are no unusual or specific medications that are recommended for ME/CFS; most of the prescribing will be with common agents such as SSRIs for mood symptoms, amitriptyline /simple analgesics for pain. Opiates are not recommended for chronic pain conditions and can contribute to fatigue issues so are not recommended for the management of ME/CFS related pain.

BACME have produced a symptom management guide (see resources at the bottom of this document for link).

## Dysautonomia symptoms

Most patients with ME/CFS will have a degree of altered Autonomic Nervous System function. There are several behavioural strategies that can help support more stable Autonomic function sometimes referred to as 'orthostatic tolerance' measures:

- **Fluid** Research has shown that people with autonomic dysfunction do not retain fluid in their circulation very well, so drinks need to be taken every 2-3 hours throughout the day aiming for 2-2.5l per day. Having 500ml of fluid on rising in the morning and prior to doing an activity can help reduce the risk of a drop in Blood Pressure.
- **Salt** If there is no evidence of high blood pressure then increasing salt intake can also help -aiming for around 6g/day (approx. 1.5teaspoons).
- **Electrolytes** Having electrolyte-based drinks can also help retain fluid in circulation better.
- **Compression** Some people find wearing long compression stockings (i.e., thigh or waist length) or tight clothing and/or underwear, can reduce the severity of their orthostatic symptoms by reducing blood pooling.
- **Bed elevation** Some people find that elevating the head of the bed by 4-6 inches is of help. This is because it alters the circulation to the kidney

resulting in a reduction in the amount of urine produced overnight and reduces salt excretion. This can help sleep by reducing the number of times needed to get up to empty the bladder and because it reduces the level of morning dehydration. It may take a few weeks for the benefit to be apparent and the strategy should be abandoned if it appears to be causing more disrupted sleep or any other escalation in symptoms.

- **Eating patterns** Eating small amounts of food regularly or 'grazing' and avoiding eating sugary foods on their own can help to stabilise blood sugar levels. Reducing or eliminating caffeine is worth considering. Lying down after eating can help people who experience an escalation in fatigue after eating.
- **Lying/Sitting/Standing** Because of the problems with being upright, taking rest lying down will be beneficial when symptoms start to escalate. However, spending long periods of time lying flat can lead to the body being less able to tolerate the effects of gravity when upright so it is important to find a careful balance between taking planned, structured rest periods laid down and then having other rest periods sat with your feet on the floor and then short periods of time standing or walking followed by a further rest period.
- **Breathing exercises** Doing deep, slow diaphragmatic breathing regularly can help activate the parasympathetic nervous system and hence can help to reduce the symptoms that come about due to exaggerated sympathetic nervous system activity. Doing regular breathing exercises over time can gradually improve sleep quality which in turn may help fatigue issues. One option is to spend 10 minutes twice a day doing deep slow breathing, breathing through the nose for 4 seconds while breathing in and 6 seconds breathing out. There are various apps which can support doing relaxation breathing exercises.

## Exercise

Deconditioning is not the cause of the symptoms of ME/CFS, but unfortunately the loss of muscle bulk and fitness which can happen because of the fatigue will aggravate the situation. Exercise needs to be done extremely carefully considering the principles of pacing i.e., stopping before the point of exhaustion and exercising at a level that does not provoke an escalation in symptoms. Research has shown some people with ME/CFS have altered aerobic pathways which means pushing to do more aerobic exercise can be counterproductive. Exercising while lying or sitting down can sometimes be more tolerable and trying things like gentle muscle strength work using resistance bands can be a good starting point. It is important that the starting point is a very small amount of activity that can be sustained every day without causing any escalation in symptoms.

## Diet

There is insufficient evidence to recommend any specific diet for the management of ME/CFS. General principles are to ensure good nutritional intake and having foods which have anti-inflammatory effects such as brightly coloured vegetables and fruit which may be of benefit along with minimising highly processed foods. Having a

variety of different foods can also help support a diverse gut microbiome. Patients may struggle to maintain a good diet due to the fatigue limiting their ability to shop, prepare and cook meals. It can be helpful to look for easy options such as tinned and frozen vegetables and freezing portions of meals, along with asking family and friends to help by preparing extra portions of their meals.

Patients who have significant bowel symptoms may try dietary alterations to see if this improves their symptoms. If a patient is excluding significant food groups from their diet, then it would be wise to refer them for dietician assessment.

### **Mood**

If a patient has significant mood or anxiety problems, it is important to treat them and depending on the severity, consider referral to appropriate primary or secondary mental health services.

### **Prognosis**

There is a lot of active research in the field of ME/CFS, but the reality is it currently remains a difficult condition to research due to the lack of consistent biological markers of illness. Consequently, data on recovery is limited.

Some patients with ME/CFS do recover so it is important to adopt an optimistic approach to its management. However, the reality for many patients is that it affects their lives for many years, and some do not make a good recovery, so it is helpful to adopt a Long-Term Condition management type approach.

It has been suggested that about 20% of ME/CFS sufferers make a full recovery, 60% make improvement and 20% continue with long term symptoms. A proportion of patients will recover sufficiently to a good level of occupational / social function but may experience relapses or setbacks triggered by a number of factors such as viral or bacterial infections or other illnesses and significant life stresses.

It can be helpful to reflect with patients about what recovery may look like. For some patients, the stressful or busy lifestyle they were leading before becoming ill may have contributed to their symptoms once they became unwell. Consequently, recovery would not be aimed at returning to that same lifestyle but more a moving on to a different way of managing demands.

## Severe ME/CFS

ME/CFS is a dynamic condition with fluctuating symptoms on a day-to-day basis and over longer periods of time. The severity of the illness can vary greatly between different people and the severity can also vary over time.

There are some people with ME/CFS who become very severely affected and this will mean they are bed bound most or all the time. They often have severe sensory sensitivity so will struggle to tolerate normal levels of light, noise and movement and will need adjustments made to accommodate for this. They will be dependent on care being provided by family, friends, or care agencies.

Many people with severe ME/CFS have other co-morbidities which can be difficult to manage in the context of them also having severe fatigue to the extent they will struggle to engage in conversations and may have significant medication sensitivities.

Some people with severe ME/CFS can have significant gastrointestinal problems which can lead to compromised nutritional intake. It is important to be alert to the risks of malnutrition even in people with normal or high BMI.

Support should be sought from relevant specialists to ensure people with severe ME/CFS have access to high quality health care. However, this can often be difficult to access due to their inability to attend hospital appointments or even engage in verbal consultations. It is likely that a range of different professionals would need to be involved and hospital admission should be considered if there are serious nutritional difficulties which cannot be managed safely at home.

If a person with severe ME/CFS requires hospital admission it can be helpful to provide information to the hospital staff regarding their care requirements so adaptations can be made where possible in the hospital setting e.g., to minimise exposure to noise and light where possible.

## Accessing Primary Care

Attending healthcare appointments in Primary Care can be a big energy demand for people with ME/CFS and can often trigger an episode of Post-Exertional Malaise.

This adds to the difficulties people with ME/CFS have accessing help, support and appropriate healthcare for their ME/CFS and also any other health conditions they have.

Primary care staff can support people with ME/CFS to access healthcare by having a flexible approach particularly regarding what mode of contact is used. Some people with ME/CFS will find telephone or video calls beneficial as it removes the demand of travel and waiting etc. Some people may find it easier to use written communication such as e-consults. However some people with ME/CFS find it more energy demanding to communicate via these methods so may prefer to attend in person but may find the environment of the waiting room problematic.

Providing a quiet place to wait, possibly with access to a bed to lie on while waiting may be a very useful strategy for some people. This will mean they are not as fatigued when entering the consulting room and will be better able to engage in the consultation.

Educating primary care staff about a patient's need to wear dark glasses and/or ear defenders to help reduce the demand of sensory stimulus can help to reduce the unhelpful judgements and comments that may sometimes happen.

Although the demand on primary care time is high, it will be appropriate for some people with ME/CFS to be seen at home. It is possible that someone with moderate ME/CFS may have times when they can leave the house and that can lead to them not being classed as housebound and therefore judged as not eligible for home visits. However, as ME/CFS is a fluctuating condition it is important to respect the patient's report of how badly they are affected at the time they are trying to access care and the potential detrimental impact that the demand of attending the surgery will have on their symptoms.

Home visits can often provide very valuable insights into the home situation and may also provide contact with formal and informal carers which will all add to the quality of care being provided.

People with severe and very severe ME/CFS will need home visits and any staff attending will need to be aware of the impact of their visit as it is likely to trigger an escalation in ME/CFS symptoms. It is helpful to respect requests to minimise movement and noise for people who have severe sensory sensitivities and keeping visits brief or taking breaks if longer or more challenging conversations are needed.



## Referral

**Children:** all children in whom you suspect a diagnosis of ME/CFS should be referred to a paediatrician. If available, once a diagnosis has been confirmed, they should be referred to a specialist ME/CFS service for support with management.

**Adults:** Most adults who are newly diagnosed with ME/CFS are likely to benefit from referral to a specialist service to support them with learning appropriate management strategies.

### **Leeds & West Yorkshire ME/CFS Service**

We are an outpatient adult service and accept referrals for people from the age of 17 upwards. We currently accept referrals from within the NHS West Yorkshire ICB (in Leeds) which is part of the West Yorkshire Integrated Care Board and wider West Yorkshire Integrated Care System (WYICS). This includes Bradford District and Craven, Calderdale, Kirklees, Leeds, and Wakefield District. This way of working together, implemented in 2022, replaces the need for accessing funding for out of area patients as was necessary previously. Despite these changes, we continue to request that referrers take into account our criteria for referral and other relevant services closest to the patients registered GP practice. We may consider referrals outside this area and we accept referrals for people with all severities of ME/CFS.

**Team Members:** We are a multidisciplinary therapy team (MDT) with practitioners from occupational therapy, nursing, physiotherapy, and dietetics. The medical input to our team is provided by a Consultant Liaison Psychiatrist and a GP with a specialist interest in ME/CFS. We also work with some past patients and supporters who help deliver or co-create a range of Service Developments.

**Location:** The service is based in the Therapy Suite, 1st Floor, Newsam Centre, Seacroft Hospital, Leeds, West Yorkshire.

**Opening times:** The service operates between 8.30am and 4.30pm, 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 or via email [Cfsme.lypft@nhs.net](mailto:Cfsme.lypft@nhs.net)

**Appointment modalities:** We are able to offer assessments in person and via video call. All patients accepted by our service will receive a comprehensive 90 minute assessment appointment which may be conducted by one of the therapy team or one of the doctors. For those patients who progress to a therapy programme we offer a group introductory session, and a family member, friend or carer can also attend that session. We then usually provide 4 sessions delivered in small groups and these are currently being delivered remotely over Video platform. We also offer individual care planning, review and therapy sessions which can be provided in person, by phone or by video call. We have a limited capacity to provide home visits

to patients who are severely affected if they live within a 30 mile radius of our base at Seacroft hospital.

### **Access Issues**

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.

For individual Video Consultations we currently use a platform developed in the NHS called Attend Anywhere and a minimum internet speed and electronic device is required. We provide booklets and materials in a range of formats.

### **Outpatient referrals**

We offer assessment and treatment to patients who meet the criteria of ME/CFS. We can also provide limited support to patients who do not meet the criteria for a diagnosis of ME/CFS if they have a pattern of fatigue which is similar to that seen in ME/CFS and fatigue is their primary debilitating symptom. Whilst we recognise there can be symptom overlap between ME/CFS and Fibromyalgia, please be aware that we are not a Fibromyalgia service.

Our therapy programme is not focused on addressing pain issues and we are not able to provide medication management for pain problems. We would only consider a diagnosis of ME/CFS if the primary symptom is fatigue with a clear Post-Exertional Malaise pattern. If pain is the primary symptom and it is the main problem impacting on function and sleep, then we would recommend referral to your local Fibromyalgia or chronic pain service.

Our medical staff are happy to provide diagnostic assessments for patients who have completed appropriate investigations prior to referral.

We are unable to request any investigations through our service and we cannot make onward referrals to services outside our trust. We therefore request that all appropriate investigations are completed through primary care prior to referral to our service. If we feel that a patient requires further investigations, we will provide relevant information to the patient's GP and we are grateful for the support from primary care staff in ensuring that patients with complex fatigue presentations are able to access relevant investigations and other specialist opinions when required.

There are no licensed medications for treating ME/CFS, so our service does not provide any medication management. There may be occasions when our team can provide suggestions to the patient's GP regarding medications which may be of use for managing some aspect of their symptoms.

#### Referral requirements:

- ✓ History of the fatigue symptoms with evidence of a post-exertional pattern
- ✓ Patient Summary to include past and current medical and mental health history and current medication
- ✓ Information regarding any other services currently involved
- ✓ Blood test results (as listed below) done in the 6 months prior to referral - please provide your local laboratory reference ranges with the results.
- ✓ Urinalysis
- ✓ BMI (please provide further relevant information if the patient has a very high or low BMI)
- ✓ Results of any other relevant tests that have been done to exclude other causes of fatigue
- ✓ Please include as much information as possible with the referral regarding what investigations have been done, especially if there are any abnormalities on the basic blood screen. Please include any secondary care correspondence relevant to the diagnosis of ME/CFS or management of symptoms.

#### Essential Blood Test results required with referral:

FBC  
U&E  
LFT  
TFT  
HBa1c  
CRP  
Calcium  
Phosphate  
Coeliac Screen  
Ferritin  
CK

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 (see webpage link)  
The service link is also available on the LTHT portal.

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 Severely Affected Pathway**

This is available to patients within 30 miles of the service base and whose needs require this level of intervention and where a home assessment component may be helpful. 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. We use a combination of remote platforms, email, home visits and telephone to provide individualised treatment.

Referral address for Outpatient and Community Rehabilitation based pathways:  
Leeds and West Yorkshire ME/CFS Service  
Therapy Suite, 1st Floor  
Newsam Centre  
Seacroft Hospital  
York Road, Leeds, LS14 6WB

Telephone enquiries: 0113 8556330/1/4

Email: [Cfsme.lypft@nhs.net](mailto:Cfsme.lypft@nhs.net)

### **Referrals for inpatient admission – National Inpatient Centre for Psychological Medicine (NICPM)**

The in-patient element of the ME/CFS service is provided by the National Inpatient Centre for Psychological Medicine (NICPM) in Brotherton Wing, at Leeds General Infirmary in the City Centre. This unit has facilities for inpatient assessment and rehabilitation of patients with severe ME/CFS. Some patients may be under our Therapy or Severely Affected pathway but require inpatient assessment. Sometimes joint assessments are undertaken prior to admission. The unit also takes direct referrals for patients from GP's. Further information regarding this service can be found on their webpage:

[www.leedsandyorkpft.nhs.uk/our-services/national-inpatient-centre-psychological-medicine-nicpm/](http://www.leedsandyorkpft.nhs.uk/our-services/national-inpatient-centre-psychological-medicine-nicpm/)

## Annual Review in Primary Care

For the majority of people, ME/CFS is a long-term condition. It is an illness that impacts on every aspect of a person's life: education, work, family life, social life, hobbies, sport etc and it can have a significant impact on their quality of life.

It is important that ME/CFS is coded as a diagnosis on a person's primary care record.

In line with other long-term conditions, it is important to offer adults with ME/CFS an annual review as a minimum level of care. Children and young people with ME/CFS should be reviewed every 6 months as a minimum. It is worthwhile adding an ME/CFS annual review recall code onto their medical record.

The NICE Guideline on ME/CFS has further information on primary care reviews and these are the things that should be covered in addition to any other factors relevant to that individual:

- their condition, including any changes in their illness and the impact of this
- symptoms, including whether they have experienced new symptoms
- self-management – ask about their energy management plan and (if relevant) their physical activity or exercise programme
- who is helping them and how they provide support
- psychological, emotional and social wellbeing
- any future plans – ask if the person is considering any changes or if they have any challenges ahead.

If a child or young person with ME/CFS is no longer under the care of a Paediatrician, then a review should be conducted in Primary Care but it may be appropriate to seek guidance from a specialist service. When reviewing children and young people with ME/CFS you may need to involve their parents or other family members but always endeavour to make sure the voice of the child or young person is heard, while also respecting the severity of their condition and how that may impact on their ability to communicate. Additional factors to consider regarding the review of children and young people:

- their developmental stage
- transitions, such as changing schools or exams
- the severity and complexity of symptoms
- the effectiveness of any symptom management.

## Resources

### **For Patients**

**NICE** guidance for patients/public:

[www.nice.org.uk/guidance/ng206/informationforpublic](http://www.nice.org.uk/guidance/ng206/informationforpublic)

**Action for ME** [www.actionforme.org.uk/](http://www.actionforme.org.uk/) provide helpful booklets on the condition, pacing, employment and have welfare rights advice and provide support for children and young people with ME/CFS

**ME Association** [www.meassociation.org.uk/](http://www.meassociation.org.uk/) links to local groups and telephone line for information and support

**British Dietetic Association** <https://www.bda.uk.com/> provides basic dietary advice on a wide range of subjects including a food fact leaflet for ME/CFS and various food intolerances/allergies.

### **Autonomic dysfunction**

[www.dysautonomiainternational.org](http://www.dysautonomiainternational.org) Large American site providing information and advice for managing autonomic dysfunction.

[www.potsuk.org/](http://www.potsuk.org/) is a UK site specifically about Postural Orthostatic Tachycardia Syndrome.

**Communication aids:** <http://www.stickmancommunications.co.uk> Website covering a variety of different conditions/symptoms providing humorous means of communicating difficulties with various products to purchase (books, pacing packs etc.) and Sunflower lanyards [www.https://hiddendisabilitiesstore.com/](http://www.https://hiddendisabilitiesstore.com/)

**Local patient support groups** exist across West Yorkshire. **See:** <https://meassociation.org.uk/information-and-support-line/localsupportgroups/>

**ME Connect Telephone Helpline** – 0344 576 5326. 365 days a year, 10am-12noon, 2pm-4pm and 7pm-9pm

### **Pregnancy and Child Care with ME/CFS;**

Foggy Friends - <https://foggyfriends.org/>

ME/CFS Parents - <http://www.mecfsparents.org.uk/>

## For Clinicians

### ME/CFS

NICE Guideline for ME/CFS: [www.nice.org.uk/guidance/ng206](http://www.nice.org.uk/guidance/ng206)

**BACME** British Association of Clinicians in ME/CFS: [www.bacme.info](http://www.bacme.info)

An introduction to Dysregulation

Symptom management guide

Therapy Guide

Severe ME/CFS guideline

Post-viral fatigue guideline.

UK services map.

Webinar presentation of the Dysregulation model available using the following link:

<https://youtu.be/vs73sl6YMXU>

**Primary Care Guide to ME/CFS** 90min presentation delivered by Dr Vikki McKeever  
GPwSI ME/CFS <https://youtu.be/jSdcLfJa44o>

**CFS/ME Research Collaborative** 2020 conference presentations

<https://www.youtube.com/playlist?list=PLJV2oZMsotON2WJSXHBx-e09WUhkKdhCI>

**Dialogues for a neglected illness** <https://www.dialogues-mecfs.co.uk/>

### Dysautonomia

[www.potsuk.org](http://www.potsuk.org)

[www.dysautonomiainternational.org](http://www.dysautonomiainternational.org)

[www.thedysautonomiaproject.org](http://www.thedysautonomiaproject.org)

YouTube videos- Dr Gupta York Cardiology, POTS/Dysautonomia

<https://www.youtube.com/watch?v=5J4-3QsPDuw>

### Hypermobility

Hypermobility Syndromes Association: [www.hypermobility.org](http://www.hypermobility.org)

RCGP Ehlers Danlos Syndromes Toolkit: <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx>

### Mast Cell Activation Syndrome (MCAS)

Mast Cell Action <https://www.mastcellaction.org/>

### Post-Viral Fatigue

Royal College of Occupational Therapists post-viral fatigue guide for patients from [www.rcot.co.uk](http://www.rcot.co.uk): <https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0>

BACME Post-Viral Fatigue management guideline available from Guidance section on: [Post-Viral Fatigue - A Guide to Management](#)

Covid 19 Post-hospital rehabilitation guideline from Lancashire Teaching hospital: <https://covidpatientsupport.lthtr.nhs.uk/#/>