

Referral Support Service

General Medicine

GM01

Chronic Fatigue Syndrome/ME

'A Definition'

Chronic Fatigue Syndrome and Myalgic Encephalomyelitis are interchangeable terms for the same condition.

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

Making a confident diagnosis of CFS/ME is very important for the patient as it allows them to access appropriate information and support to help them manage their condition.

Chronic Fatigue Syndrome/ME 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 feature.

General Points

DIAGNOSIS

Detailed history taking will be required to make an accurate diagnosis. This may require several appointments over a period of time or a long appointment to fully evaluate all symptoms. The symptoms of CFS/ME overlap with other disorders, so other conditions need to have been considered.

Fatigue

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

In CFS/ME the normal recovery systems of the body are not working properly so unlike the 'normal' fatigue everyone can feel, the fatigue of CFS/ME is often described as feeling very different. The key features of the fatigue in CFS/ME are:

- Sleep/Rest is unrefreshing
- Activity causes an escalation in fatigue and/or malaise often delayed by 24hours or more with slow recovery over days.

Patients may not have recognised the post-exertional pattern and are often caught in a 'Boom and Bust' cycle whereby they push themselves to do more on a better day then feel more ill the following few days. Prompting patients to keep an activity/fatigue diary can help them to identify if this pattern is present.

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Other factors with regard to fatigue required for diagnosis:

- New onset (i.e. not lifelong) – maybe triggered by an event/illness or more gradual onset
- Lasting more than 4 months for adults or 3 months for children
- Causing significant reduction in daily activities

Additional symptoms

In addition to fatigue, patients with CFS/ME **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 CFS/ME. 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
- general 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 Dysfunction:

- Dizziness/ feeling faint/ delayed postural hypotension
- Palpitations including postural orthostatic tachycardia syndrome (POTS)
- Urinary frequency/bladder dysfunction
- Nausea and irritable bowel symptoms
- Exertional dyspnoea

Neuroendocrine:

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

Pain:

- Headaches
- Muscles pains
- Joint pains

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Mood:

- Anxiety
- Depression

Sleep disturbance:

- Altered sleep rhythm
- Unrefreshing sleep

(This list incorporates elements from The CDC Criteria (Fukuda et al) and The Canadian Guidelines for diagnosing CFS/ME)

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.

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

- **FBC**
- **U&E**
- **LFT**
- **TFT**
- **CRP**
- **Hba_{1c} IFCC**
- **Calcium & Phosphate**
- **Coeliac Screen**
- **Creatinine Kinase**
- **Urinalysis**
- Ferritin is essential in children and recommended in adults (aim for >50)
- Vitamin D levels are also worth checking and correcting if low

In CFS/ME 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 CFS/ME.

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 CFS/ME so investigations can be planned with this in mind.

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

COMMON ALTERNATIVE OR CONTRIBUTING CONDITIONS TO CONSIDER LOOKING FOR:

- ➔ Sleep apnoea (obstructive and central)

- Mental health conditions e.g. primary anxiety/depression, OCD, PTSD, eating disorders, dysthymia, autism
- Primary sleep disorders e.g. Hypersomnia (sleepiness rather than fatigue)
- Chronic infection e.g. hepatitis, streptococcal infection, Lyme disease
- Rheumatological disease e.g. psoriatic arthropathy, Rheumatoid Arthritis
- Hypermobility Spectrum Disorder (consider this in patients with joint hypermobility and gradual onset of multiple additional symptoms)
- Substance misuse e.g. alcohol, caffeine, cannabis
- Medication side effects e.g. opiates

Children: all children in whom you suspect a diagnosis of CFS/ME should be referred to a paediatrician.

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 CFS/ME 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 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.

Education

Patients will need to develop an understanding of their condition in order 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. (see end of document for patient resources)

Activity vs Exercise

It is important for patients 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 CFS/ME management.

Complete rest will not make CFS/ME better – more likely it will result in deconditioning and escalation of fatigue. Equally, increasing exercise will not make CFS/ME better and can often cause escalation in a patient's symptoms.

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 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 also change between different types of activity. For example: do 10 minutes of housework followed by 15 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 CFS/ME. 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 CFS/ME develop intolerance to multiple medications. It is therefore prudent to start any new treatment at the lowest possible dose and titrate up very slowly. Make sure patients know to return for review so dose adjustments can be made and medication that is ineffective is stopped.

There is no known pharmacological treatment or cure for CFS/ME. However, symptoms of CFS/ME should be managed as in usual clinical practice. Clinician must adhere to the formulary when making prescribing decisions. If chronic pain is a predominant feature, healthcare professionals should consider referral to a pain management clinic.

Prescribing of low-dose tricyclic antidepressants, specifically amitriptyline, should be considered for people with CFS/ME who have poor sleep or pain. Tricyclic antidepressants should not be offered to people who are already taking selective serotonin reuptake inhibitors (SSRIs) because of the potential for serious adverse interactions.

Patients who have significant bowel symptoms often 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. There is no evidence based information available regarding diet but the BDA website may help (see website list at end)

If a patient has significant mood or anxiety problems, it is important to refer them to mental health services for support and advice on management.

PROGNOSIS

There is a lot of active research in the field of CFS/ME 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 CFS/ME 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 chronic disease management type approach.

It can also be helpful to reflect with patients about what recovery may look like. For some patients the stressful lifestyle they were leading before becoming ill may have contributed to them becoming 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.

Recent research at Bristol University looked at recovery rates in children with CFS/ME. They found a 60-80% recovery rate for children who had specialist care but only a 6-8% recovery rate for those without specialist care.

REFERRAL INFORMATION

Children: all children in whom you suspect a diagnosis of CFS/ME should be referred to a paediatrician.

Adults:

Referral requirements:

- ✓ Blood tests as listed above done in the 6 months prior to referral-please enclose results with referral.
- ✓ Urinalysis
- ✓ BMI
- ✓ Please include as much information 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 CFS/ME or management of symptoms.
- ✓ Completed pathway screening form [Pathway Screening Form](#)

Where to refer

The preferred providers in North Yorkshire for CFS/ME management are:

- Yorkshire Fatigue Clinic – Vale of York CCG; Hambleton, Richmondshire & Whitby CCG; Scarborough & Ryedale CCG.
- Harrogate CFS/ME Adult Team – Harrogate & Rural CCG.

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Yorkshire Fatigue Clinic

For any patient you wish to refer through the CFS/ME pathway you will need to complete the [Pathway Screening Form](#). The form should be sent with the standard referral letter and copies of required blood tests/investigations.

If you wish to refer a patient with persistent fatigue outside of the criteria, these should be sent directly to **the Individual Funding Request Panel for consideration**. In these cases the pathway screening form can be used to support why the patient does not meet the criteria.

About the service

The Yorkshire Fatigue Clinic is a rehabilitation service based in Clifton Moor, York and is run by Sue Pemberton, Specialist Occupational Therapist. Sue set up the Leeds Service over 28 years ago and subsequently moved to York and established the Yorkshire Fatigue Clinic in 2012 as an independent provider. The small team includes 3 additional OT's and sessional input from a GPwSI. The vast majority of their work is NHS funded.

This service does not provide any investigative work or prescribing so it is important that all of this is done through primary care.

York patients aged 13 and over with a confirmed diagnosis of CFS/ME are currently funded for an initial assessment which includes an assessment consultation, information workshop and a care planning session. Therapy will be provided individually or in group format, access to home based treatment and Skype is also available. A typical treatment package is around 10 sessions.

Patients who do not meet the criteria for a diagnosis of CFS/ME but have fatigue symptoms that would respond to the same kind of fatigue management strategies can be **referred to the IFR panel for funding consideration, if clinical exceptionality can be demonstrated**. Funding is not routinely commissioned for these patients so it needs to be applied for.

The service is happy to provide advice and training for any health professionals or social care staff when required. They can be contacted at yfc.admin@nhs.net

PATIENT INFORMATION LEAFLETS/PDAs

Books:

- Fighting Fatigue: a practical guide to managing the symptoms of CFS/ME (Pemberton & Berry 2009),
- CFS 'the facts' (Campling and Sharp, 2008)

Apps:

- **ME/CFS dairy** available for Apple and Android
- There are lots of useful apps to support relaxation training/mindfulness etc. which patients can be encouraged to research and use.

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Websites:

- **NICE** guidance for patients/public <https://www.nice.org.uk/guidance/cg53/ifp/chapter/About-this-information>
- **Action for ME** <http://www.actionforme.org.uk/> (provide helpful booklets on the condition, pacing, employment and welfare rights, includes section for children/young people)
- **ME Association** <http://www.meassociation.org.uk/> (links to local groups and telephone line for information and support)
- **Yorkshire Fatigue Clinic** website <http://www.yorkshirefatigueclinic.co.uk/>
- **British Dietetic Association** <https://www.bda.uk.com/> provides basic dietary advice on a wide range of subjects including a food fact leaflet for CFS and various food intolerances/allergies.
- **Autonomic dysfunction** – <http://www.dysautonomiainternational.org> American site providing information and advice for managing autonomic dysfunction- some useful tips on types of exercise that can be tried. <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 the patient with humorous means of communicating their difficulties with various products to purchase (keyring cards, books, pacing packs etc.)
- **Local patient support group/online community** <http://www.york-me-community.org/>

PROFESSIONAL RESOURCES

- **BACME** – British Association for CFS/ME professionals - symptom and therapy guide, services map, discussion forums for members <http://www.bacme.info>
- **Yorkshire Fatigue Clinic:** <http://www.yorkshirefatigueclinic.co.uk/>
- **RCGP** free online learning module on CFS/ME <https://rcgpportal.force.com/s/lt-event?site=a0d0Y00000AeOP6QAN&id=a1U0Y00000DfTdCUAV>
- **Hypermobility syndromes:** <http://hypermobility.org/>
RCGP Ehlers-Danlos Toolkit (includes information on mast cell activation and autonomic dysfunction): <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx>
- **POTS section for medics** http://www.potsuk.org/gp_guide