

# Chronic Fatigue Syndrome/ Myalgic Encephalopathy (CFS/ME) - Paediatric Full Clinical Guideline

Reference no.: CH CLIN G 93/ Dec 17/v003

## 1. Introduction

CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalopathy) in children is a chronic disabling illness of uncertain and probably complex causation. Paediatricians have an important role to play in supporting the child or young person and their families and in co-ordinating multidisciplinary management.

Recognising the common presentation of CFS/ME in children and young people, and understand the impact chronic illnesses have on the family, should be part of the core competences of all paediatricians.

## 2. Aim and Purpose

- To increase knowledge and understanding among those working within paediatrics about CFS/ME in children and young people.
- To give paediatricians confidence in making a positive diagnosis, and to ensure that young patients with CFS/ME are optimally managed.

## 3. Definitions

The patient population is any child/young person up to the age of 18 referred to a paediatrician for assessment with debilitating fatigue.

## 4. Main body of Guidelines

Successful implementation of this policy involves a multidisciplinary approach to education and training.

### Background

The UK prevalence of CFS/ME in children and young people is 50-100/100,000 with the highest prevalence in adolescents. As yet there is no published evidence about incidence rates with current data being based on population surveys. Evidence for gender difference in CFS/ME is inconclusive but studies have shown increased incidence in girls to boys by 3:1

Studies have shown mean illness duration was between 37 and 49 months and recovery was better in children than in adults. However there is evidence that 5-10% of young people can be incapacitated by the illness for years.

**Clinical features**

There are a number of common clinical features seen in children and young people with CFS/ME. These include

<b>Common Symptoms</b>	<b>Less Common symptoms</b>
Fatigue associated with exercise or activity	Feeling hot or cold
Preceding acute illness	Dizziness
severe malaise	Cough
Headaches	Vision or hearing disturbances
Sleep disturbances	eye pain/increased light sensitivity
Concentration difficulties	weight gain or loss
Memory impairment	muscle weakness
Depressed mood	lack of energy for usual activities
Myalgia/muscle pain	Diarrhoea
Abdominal pain and arthralgia/joint pain	Symptoms or diagnosis of depression/anxiety or other psychological conditions
Nausea	
Sore throat	
Tender Lymph nodes	

**Making the Diagnosis**

There are no diagnostic criteria for CFS/ME in young people or children. To make a diagnosis; symptoms should persist for 3 months and other diagnoses must have been excluded.

- Making a diagnosis requires careful history taking, thorough clinical examination and excluding other differential diagnoses by performing some investigations (see below).
- An initial family history should include enquiry into chronic illness, particularly CFS/ME or similar condition in a family member.

Consideration should be given to providing a 'double slot' on first meeting in outpatients to allow time for clinical history and examination.

**Clinical Examination**

A thorough examination with symptoms of CFS/ME should be undertaken at the first consultation to exclude any other underlying illnesses. These include

- **General examination including height, weight and head circumference.**
- **A neurological examination including ophthalmology examination.**
- **Examination for Lymph node/spleen/tonsil enlargement**
- **Palpation of sinuses (to identify chronic sinusitis)**
- **HR and Lying and standing BP**

### **Investigations**

Routine tests on **all** patients include:

- **FBC, ferritin, and film- to exclude anaemia and leukaemia.**
- **ESR and CRP – to rule out an autoimmune or chronic condition.**
- **Blood glucose for diabetes mellitus.**
- **U+Es- looking for Addison’s and renal impairment.**
- **CK for muscle disease**
- **Thyroid function**
- **LFTS – looking for hepatitis**
- **Urine tested to exclude diabetes / renal disease and urinary tract infection.**

Viral titres to impute or exclude current viral infection are not recommended apart from EBV IgM and IgG and EBNA

### **Communicating the diagnosis**

- To avoid increased anxiety, it is important to explain to the patient and family that CFS/ME is a *possible* diagnosis as soon as possible, while emphasising that before making this diagnosis other possibilities need to be excluded.
- Once the diagnosis has been made, it should be communicated to the patient and their families as soon as possible. Giving a diagnosis for their symptoms will reassure that other severe illnesses have been excluded, but it needs to be communicated that alternative diagnoses have been ruled out.
- The reasons for a positive diagnosis should be communicated to the patient and families but also documented in the clinical notes.

### **Management**

**There is no single approach to the management of CFS/ME.**

**As a minimum for all children with CFS/ME the plan should include:**

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| <ul style="list-style-type: none"><li>• Activity management advice including establishing a baseline of activity level/sleep pattern and gradual increases as appropriate.</li><li>• Advice and symptomatic treatment as required.</li><li>• Regular review of progress.</li></ul> |
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It is important to work with the patient, their families and other members of the multidisciplinary team who have regular contact with children and families suffering with CFS/ME (see referral section below).

### **Paediatric Review**

Once the diagnosis has been made, the paediatrician needs to arrange regular reviews with the patient and their families

Within this review, the paediatrician will provide:

- Monitor the progress of the rehabilitation program.
- If a relapse occurs, the baseline activity should be reassessed and the paediatrician should reassure that functional level will improve.
- If no improvement at 6 months, reassessment of the management plan is needed
- Deterioration in abilities requires a reassessment sooner.
- Provide symptomatic treatment.

## **Advice and Symptomatic Treatment**

### **Sleep/Rest Management**

- A good history of the patients sleeping pattern and hygiene should be recorded by the Paediatrician prior to any interventions being started.
- Provide tailored sleep management about:
  - Role and effect of disordered sleep in CFS/ME
  - Common changes in sleep pattern seen in CFS/ME that may worsen fatigue ( insomnia, hypersomnia, sleep reversal, altered sleep-wake cycle)
  - Sleep hygiene – including avoiding caffeine/large meals before bedtime, Set times for sleep and awakening etc
  - Gradual changes to sleep pattern
- Do not encourage daytime sleeping and naps as they may disrupt sleep-wake cycle.
- Give advice on how to introduce rest periods, including;
  - Limiting to 30 minutes at a time
  - Use of relaxation techniques ( breathing techniques or guided visualisation)
  - Introducing 'low level' physical and cognitive activities
- Review rest periods regularly

### **Dietary Advice**

- Diet can be poor in those with CFS/ME due to fatigue/nausea or lack of appetite.
- Advice that a well-balanced diet is important but can be difficult due to symptoms of nausea and lack of appetite.
- Restrictive diets are usually not recommended unless problems with food intolerance or allergy.
- Referral to the dietician may help in patients with unbalanced diets or difficulty with eating.
- A nutritional plan with the child and family is important in those with severe CFS/ME, especially in those with severe weight loss.

### **Pain Management**

- Simple analgesia or non-pharmacological methods should be used for joint and muscle pain.

- If there is no improvement with simple measures, referral to the Pain Specialist nurse, physiotherapist or Clinical Psychologist may help with management and perception of the pain.
- Medication such as low-dose Amitriptyline or Nortriptyline can be used in those who are experienced with using them.

### **Treatment of depression**

- Referral to Paediatric Liaison Team, CAMHS is important for those with mood and emotional disorders associated with CFS/ME.
- Treatment should be started by those confident in using the medication and in those with severe mood disorder.

### **Education**

- Liaison with school and other education professionals is important for those with CFS/ME and it is important to agree an appropriate management plan with school.
- A flexible approach may be needed these include home tuition and using equipment that allows slow reintegration into education.
- If needed, the department of Education and Skills has produced statutory guidance in relation to children and young people unable to attend school because of a medical condition (see [www.dcsf.gov.uk](http://www.dcsf.gov.uk)).

### **Referrals**

- Those patients diagnosed with mild CFS/ME may not need any further assistance, however there are many other health professionals who deal with those suffering from CFS/ME.
- When mobility and /or daily living is affected by CFS/ME, referral to physiotherapy and occupational therapy for assessment and appropriate treatment may be required.
- For those with difficulties in managing pain referral to the Pain Nurse Specialist for relaxation techniques.
- In cases of moderate to severe CFS/ME there is nearly always a strong overlay with family relationship problems. In these cases referral to Clinical Psychology will be necessary.
- If there are concerns about self harm, eating disorders or severe depression, refer to the Paediatric Liaison Team/ CAMHS as appropriate.

**Contact information for members of the multidisciplinary team can be found in appendix 2**

### **Interventions**

- CBT may be of benefit in children and young adults with CFS/ME as suggested by extrapolated evidence in adults.
- Children/Young children with CFS/ME should be considered for graded exercise or activity programmes supervised by an experienced therapist.
- Prolonged bed rest should be avoided (unless severe CFS/ME) as reconditioning can worsen fatigue and weakness.

**Inpatient care**

Majority of children with CFS/ME can be managed on an outpatient basis with support from the GP and paediatric multidisciplinary team. However, there may be circumstances when admission to hospital maybe helpful.

**Handover of care**

It may be necessary to make arrangements to hand over care to adult services. Identification of the appropriate health professional to take over care and appropriate handover arrangements must be in place before discharging to the adult service -usually rehab services

**Further information for families**

Patients and families suffering with CFS/ME want to find out as much information as possible. Nationally recognised charities are more likely to provide mainstream advice than individuals or small support groups.

Patient information sheets will be available in outpatients for patients and their families.

**5. References (including any links to NICE Guidance etc.)**

- Diagnosis and Management of CSF/ME in adults and children, NICE August 2007 .
- Evidence based Guideline for the Management of CFS/ME in Children and Young people , Royal College of Paediatric and Child Health, December 2004.
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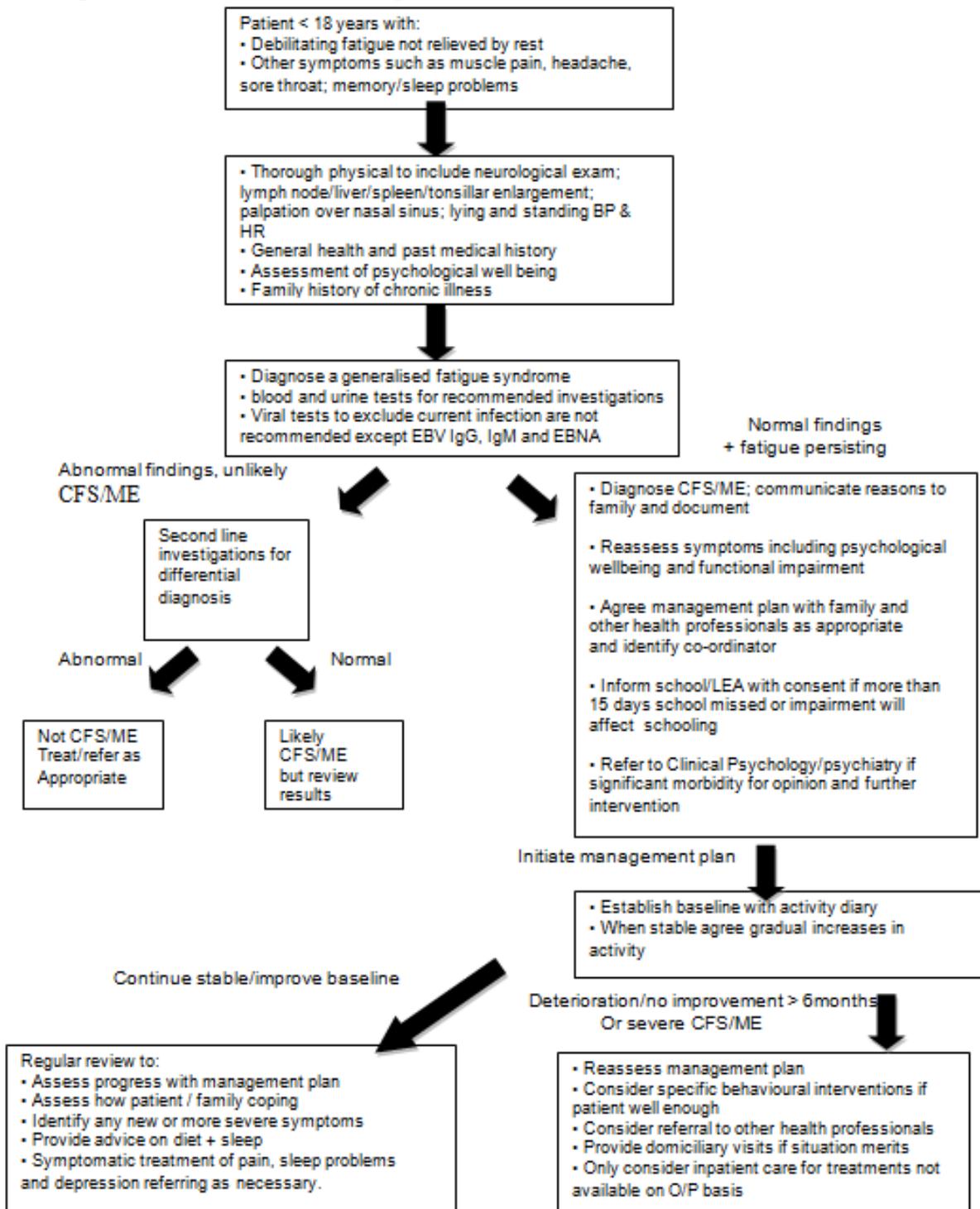
**6. Documentation Controls**

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Review Date:	December 2020
Key Contact:	Dr Vanessa Cox

**7. Appendices**

**Appendix 1**

**Figure One- Flow chart for management of CFS/ME**



## **Appendix 2**

### **Contact information for Multidisciplinary team members**

**Occupational Therapy:** Mel Bruder, Children's Hospital 01332 785541

**Physiotherapy:** Penny Sutherland, Children's Hospital 01332 785539

**Pain Nurse Specialist:** Liz Taylor, Children's Hospital

**Psychiatric team:** Paediatric Liaison Team, CAMHS, The Mill, Lodge Lane, Derby

01332 291794

**Clinical Psychology team:** Dr Ayishah Foulds. Children's Hospital

**Paediatric dietetic team:** Derby Hospital Children's Hospital