

WOMEN'S HEALTH AND PAEDIATRICS
PAEDIATRIC DEPT

Chronic Fatigue Syndrome

Amendments			
Date	Page(s)	Comments	Approved by
Sept 2015	New Guideline		Paediatric Guideline Group
March 2018	2-7	Whole document review Diagnosis change New symptoms added Change to investigations Links to specialist centres New algorithm Additional patient resources	Paediatric Guideline Group

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In Consultation with:

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Target Audience: Doctors, nurses and support staff working in Paediatrics

Impact Assessment Carried Out By:

Comment on this document to: Dr Baksh Consultant Paediatrician

Chronic Fatigue Syndrome

(Also known as Myalgic Encephalomyelitis/encephalomyelopathy)

What is CFS/ME

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a protracted and persistent illness that produces a variety of debilitating effects in children and young people (C&YP). While a hallmark symptom of CFS/ME is profound fatigue, sufferers report a wide variety of concomitant symptoms including post-exertional malaise, body, myofascial and/or joint pain, cognitive difficulties, unrefreshing or disturbed sleep, headaches and sore throat. Some symptoms are more common than others; however, the condition is characterized by unique symptom patterns and unpredictable symptom severity, which further complicates both treatment and prognosis. Symptoms are also exacerbated by periods of physical illness and emotional stress.

Epidemiology

There is a lack of epidemiological data for the UK, so population estimates are based on extrapolations from other countries. Overall, evidence suggests a population prevalence of at least 0.2–0.4%. This means that a general practice with 10,000 patients is likely to include up to 40 adults and C&YP with CFS/ME; half of these people will need input from specialist services.

Aetiology

CFS/ME may or may not be triggered by a virus. There are many potential aetiologies for CFS/ME, including neurological, endocrine, immunological, genetic, psychiatric and infectious causes which have been investigated, but the diverse nature of the symptoms cannot yet be fully explained.

Symptoms

Consider the possibility of CFS/ME if a C&YP has:

- Profound fatigue with **all** of the following features:
 - new or had a specific onset (that is, it is not lifelong)
 - persistent and/or recurrent
 - unexplained by other conditions
 - has resulted in a substantial reduction in activity level
 - characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)

And

- one or more of the following symptoms:
 - difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep–wake cycle
 - muscle and/or joint pain that is multi-site and without evidence of inflammation
 - headaches
 - painful lymph nodes without pathological enlargement
 - sore throat
 - cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing
 - physical or mental exertion makes symptoms worse
 - general malaise or 'flu-like' symptoms
 - dizziness and/or nausea
 - palpitations in the absence of identified cardiac pathology
 - abdominal pain, loose stools
 - reported less often include feeling too hot or cold, cough, eye pain/increased sensitivity to light (photophobia), vision or hearing disturbances (hyperacusis), weight loss or gain

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History, Examination and Investigations

A full history (including exacerbating and alleviating factors, sleep disturbance and intercurrent stressors) should be taken, and a physical examination and assessment of psychological wellbeing should be carried out.

A child or young person who has symptoms suggestive of CFS/ ME should be referred to a paediatrician for assessment to exclude other diagnoses within 6 weeks of presentation.

The following tests should usually be done:

- urinalysis for protein, blood and glucose
- FBC, U&Es, LFTs (and thyroid peroxidase antibodies), ESR, CRP
- random blood glucose
- coeliac screen (tissue transglutaminase antibodies and total serum IgA)
- serum calcium
- creatine kinase
- Vitamin D levels
- serum ferritin levels
- autoimmune screen
- GF screen, EBV serology

Clinical judgement should be used when deciding on additional investigations to exclude other diagnoses.

Extensive serological testing should not be routinely carried out unless the history is indicative of an infection. Depending on the history, tests for the following infections may be appropriate:

- chronic bacterial infections, such as borreliosis
- chronic viral infections, such as HIV or hepatitis B or C
- latent infections, such as toxoplasmosis, cytomegalovirus

Diagnosis

A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for 3 months in a C&YP. The diagnosis should be made or confirmed by a paediatrician.

Management

1. Symptoms

- There is no known pharmacological treatment or cure for CFS/ME. However, symptoms of CFS/ME should be managed as in usual clinical practice.
- Specific drug treatment for C&YP with CFS/ME should be started by a paediatrician. However, prescribing may be continued in primary care, depending on the preferences of the patient and their carers, and local circumstances.

2. Diet

- Healthcare professionals should emphasise the importance of eating regularly, and including slow-release starchy foods in meals and snacks. The physiological consequences of not doing so should be explained to the C&YP with CFS/ME.
- If a person experiences nausea as part of CFS/ME, this should be managed conventionally, including giving advice on eating little and often, snacking on dry starchy foods and sipping fluids. The use of anti-emetic drugs (e.g. Buccastem SL) should be considered only if the nausea is severe.
- Although exclusion diets are not generally recommended for managing CFS/ME, many people find them helpful in managing symptoms, including bowel symptoms. If a person with

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3. Sleep

- Identify the common changes in sleep patterns seen in CFS/ME that may exacerbate fatigue symptoms (such as insomnia, hypersomnia, sleep reversal, altered sleep–wake cycle and non-refreshing sleep).
- Provide general advice on good sleep hygiene.
- Introduce changes to sleep patterns gradually.
- Melatonin may be considered for C&YP with CFS/ME who have sleep difficulties, but only under specialist supervision because it is not licensed in the UK.
- C&YP with CFS/ME should be advised that excessive sleep does not generally improve physical or mental functioning, and excessive periods of daytime sleep or frequent napping may further disrupt the sleep–wake cycle.

4. Rest Periods

These are a component of all management strategies for CFS/ME. Advise patients on the role of rest, how to introduce rest periods into their daily routine, and the frequency and length appropriate for each person. This may include:

- Limiting the length of rest periods to 30 minutes at a time.
- Introducing 'low level' physical and cognitive activities (depending on the severity of symptoms).
- Using relaxation techniques.

5. Equipment to maintain independence

- Referral to physiotherapy is important to support graded activity programmes
- For patients with moderate or severe CFS/ME, providing or recommending equipment and adaptations (such as a wheelchair) should be considered as part of an overall management plan, taking into account the risks and benefits for the individual patient. This may help them to maintain their independence and improve their quality of life.

6. Education

- Healthcare professionals should work closely with social care and education services to ensure a common understanding of the goals of the C&YP with CFS/ME. The use of a flexible approach should be discussed, including home tuition and use of equipment that allows a gradual reintegration into education.
- For patients with prolonged school absence it would be useful to formulate a graded re-entry timetable in conjunction with the C&YP, parents and school.
- Time in education should not be used as a sole marker of progress of CFS/ME, and education should not be the only activity a person undertakes. There should be a balance between time spent attending school or college and doing homework, and time spent on home and social activities.

7. Psychology

- Patients who are struggling with the impact of CFS/ME should be referred for psychological support.

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8. Referral to specialist CFS/ME care

- within 6 months of presentation for people with mild CFS/ME
- within 3–4 months of presentation for people with moderate CFS/ME symptoms
- immediately for people with severe CFS/ME symptoms
- GPs can refer to the Expert Patients Programme

BATH: www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/info.asp

UCLH: <https://www.uclh.nhs.uk/OURSERVICES/SERVICEA-Z/INTMED/IMCFS/.../refer.asp>

Treatments offered at specialist CFS/ME centres include:

- cognitive behavioural therapy
- graded exercise therapy
- activity management programmes
- group therapy

Prognosis

- The prognosis in children and young people is generally positive and most will make a full recovery but this may be over several months. A few may experience persisting symptoms.

References

1. Guidance adapted from 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME in adults and children' NICE clinical guideline 53, issued August 2007. Available at

<http://www.nice.org.uk/nicemedia/live/11824/36193/36193.pdf>

2. Evidence Based Guideline for the Management of CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalopathy) in Children and Young People December 2004

<https://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20CFS.pdf>

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Clinical Algorithm for Management CFS/ME

Patient < 18 years with

- Debilitating fatigue not relieved by rest
- Other symptoms e.g. headache, sore throats, memory loss, poor sleep

- Thorough physical to include neurological exam; lymph node/liver/spleen/tonsillar enlargement; palpation over nasal sinus; lying and standing BP & HR
- General health and past medical history
- Assessment of psychological well being
- Family history of chronic illness
- Listen to patient; explore all symptoms/ functional impairment

- Diagnose a generalised fatigue syndrome
- Blood and urine tests for recommended investigations
- Viral tests to exclude current infection are not recommended apart from EBV IgM, IgG

Abnormal results, probably not CFS/ME

Normal findings and debilitating fatigue

- Second line investigations for differential diagnosis

- Diagnose CFS/ME; communicate reasons to family and document
- Reassess symptoms including psychological well being and functional impairment
- Agree management plan with family and other health professionals as appropriate
- Inform school/LEA with consent if more than 15 days school missed or impairment will affect schooling
- Refer to psychology/psychiatry if significant morbidity and no local expertise or for specific behavioural interventions

Normal

Abnormal

- Likely CFS/ ME but review results

Not CFS/ ME

- Treat and refer as appropriate
- If ANA \geq 1: 320 refer to Dr. Baksh

Initiate management plan

- Establish baseline with activity diary

- When stable agree gradual increases in activity

Continued stable, improving

Regular review to:

- Assess progress with management plan
- Assess how patient / family coping
- Identify any new or more severe symptoms
- Provide advice on diet + sleep
- Symptomatic treatment of pain, sleep problems and depression referring as necessary.

Deterioration, no improvement after 6

- Reassess management plan
- Consider specific behavioural interventions if patient well enough
- Consider referral to other health professionals

NICE recommends referral to specialist tertiary team – UCLH, BATH

- Within 6 months of presentation with mild CFS/ME
- Within 3–4 months with moderate CFS/ME
- Immediately with severe CFS/ME symptoms

<http://www.rcpch.ac.uk/system/files/protected/page/Leaflet.pdf>

<http://www.ayme.org.uk>

<http://www.actionforme.org.uk> (includes advice for the newly diagnosed and pacing activities)

<https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/>

www.rcpsych.ac.uk/healthadvice/.../parentscarers/chronicfatiguesyndrome.aspx

www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/info.asp

www.childrenandyoungpatients.uclh.nhs.uk/13-19/your.../chronic-fatigue-syndrome/

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