Ashford and St. Peter's Hospitals
NHS Foundation Trust

Paediatric Chronic Fatigue Syndrome

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Guideline History		
Date	**Comments**	**Approved By**
Sept 2015	New Guideline	Paediatric Guideline Group
March 2018	Whole document Review. Diagnosis change. New symptoms added. Change to investigations.Links to specialist centres. New algorithm. Additional patient resources	Paediatric Guideline Group
February 2026	Whole document review. Added epidemiological data. Diagnosis criteria change. Change to management. Flare-up and relapse guidance. Links to specialist centres updated. Additional patient resources	Paediatric Guideline Group

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Contents

		Page
1.	Guideline	
	a. Introduction	3
	b. Symptoms	3-4
	c. History, Examination and Investigations	4-5
	d. Diagnosis, Management and onward Referral	6-9
	e. Flow chart	10
	f. Patient resources	11
2.	Supporting References	12
3.	Supporting Trust Guidelines	
4.	Guideline Governance	
	a. Scope	
	b. Purpose	
	c. Duties and Responsibilities	
	d. Approval and Ratification	
	e. Dissemination and Implementation	
	f. Review and Revision Arrangements	
	g. Equality Impact Assessment	
	h. Document Checklist	
5.	Appendices	

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). It is a complex, multi-system, chronic medical condition that has considerable personal, social and economic consequences and a significant impact on a person's quality of life, including their psychological, emotional and social wellbeing. 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. Recent data from the UK Biobank suggest that there are over 250,000 people in England and Wales with ME/CFS, with about 2.4 times as many women affected as men. ME/CFS can affect people of all ages.

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:

1. the following 4 symptoms for a minimum of 4 weeks:

(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.

2. Reduced ability to engage in occupational, educational, social or personal activities is significantly from pre- illness level
3. Symptoms are **not** explained by other condition

This may or may not be associated with **one or more** of the following symptoms:

- muscle and/or joint pain that is multi-site and without evidence of inflammation
- headaches
- painful lymph nodes without pathological enlargement
- sore throat
- 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
- orthostatic intolerance including palpitation, dizziness, fainting on standing or sitting upright from a reclining position.
- 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

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 peroxidise 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

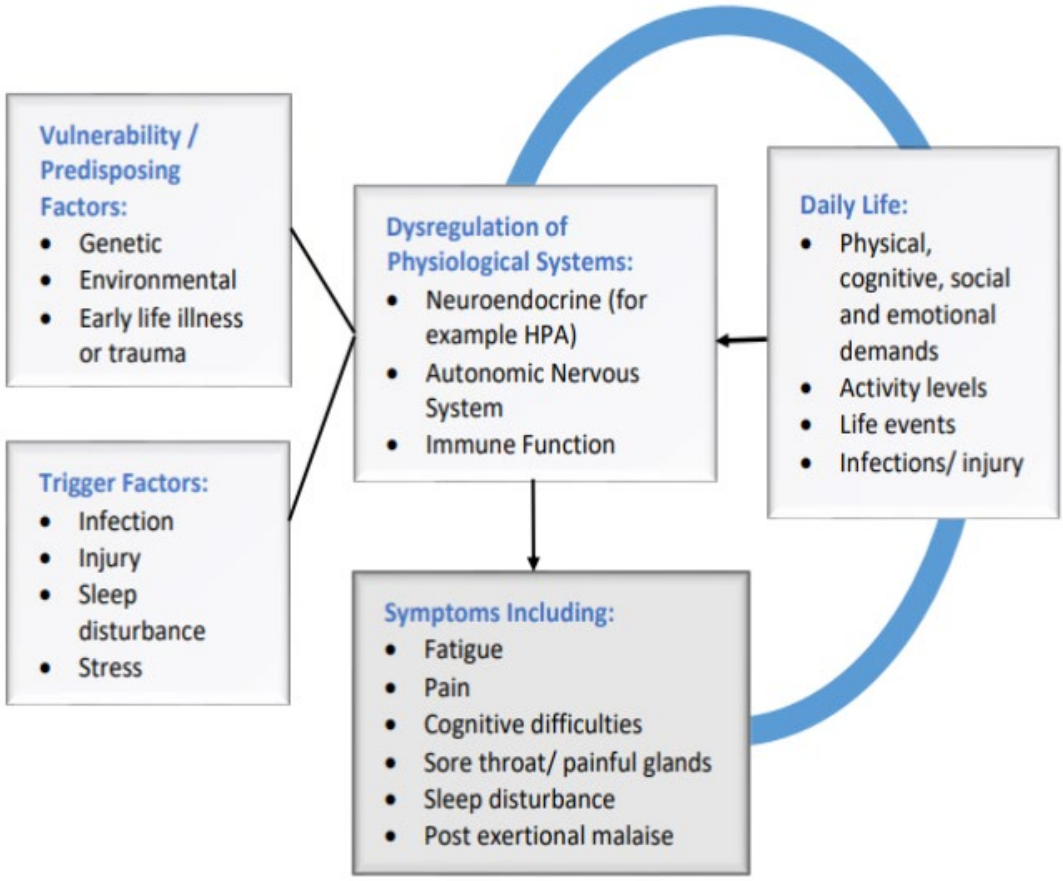
- GF screen, EBV serology

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

Figure 1: A Pragmatic Model for ME/CFS



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 CFS/ME undertakes an exclusion diet or dietary manipulation, healthcare professionals should seek advice from a dietician because of the risk of malnutrition.

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 that is based on an individualised approach with regards to people with ME/CFS who choose to undertake a physical activity or exercise programme.
- Physiotherapists work with the person to establish an individual activity pattern within their current energy limits that minimises their symptoms.
- 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.

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/our-services/find-service/integrated-medicine/chronic-fatigue-syndrome-and-fibromyalgia-service

9. Social care and Safeguarding

- Discuss sensitively with the person and their family or carers (as appropriate) how social care may benefit them. Explain that it can help the person living with ME/CFS as well as provide a route to support for families and carers through a formal carer's assessment.
- Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect.

- If a person with confirmed or suspected ME/CFS needs a safeguarding assessment, directly involve health and social care professionals who have training and experience in ME/CFS as soon as possible*
- If a person with confirmed or suspected ME/CFS needs to be assessed under the Mental Health Act 1983 or the Mental Capacity Act 2005 directly involve health and social care professionals who have training and experience in ME/CFS as soon as possible
- Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months, and more frequently if needed, depending on the severity and complexity of their symptoms.

10. Access to care and support

- Health and social care organisations should ensure that people with ME/CFS can use their services by adapting the timing, length and frequency of all appointments to the person's needs
- If a person with ME/CFS misses an appointment: - do not discharge them for not attending and discuss the reasons as it could be due to their symptoms worsening or cognitive difficulties

FLARE UP

Worsening of symptoms, more than would be accounted for by normal day-to-day variation, that affects the person's ability to perform their usual activities. Flare-ups may occur as pain or post exertional malaise spontaneously or be triggered by another illness, overexertion or other triggers.

Flare up will need patients to:

- Identify and minimise triggers
- Temporarily reduce their activity levels
- Review their care and support plan

RELAPSE

A sustained and marked exacerbation of symptoms lasting longer than a flare-up and needing a substantial and sustained adjustment to the person's energy management.

Relapse will need patients to:

- increasing the frequency or duration of rest periods
- reassessing energy limits to stabilise symptom
- Reduction/Cessation of some activities

Treatment

Treatments offered at specialist CFS/ME centres include:

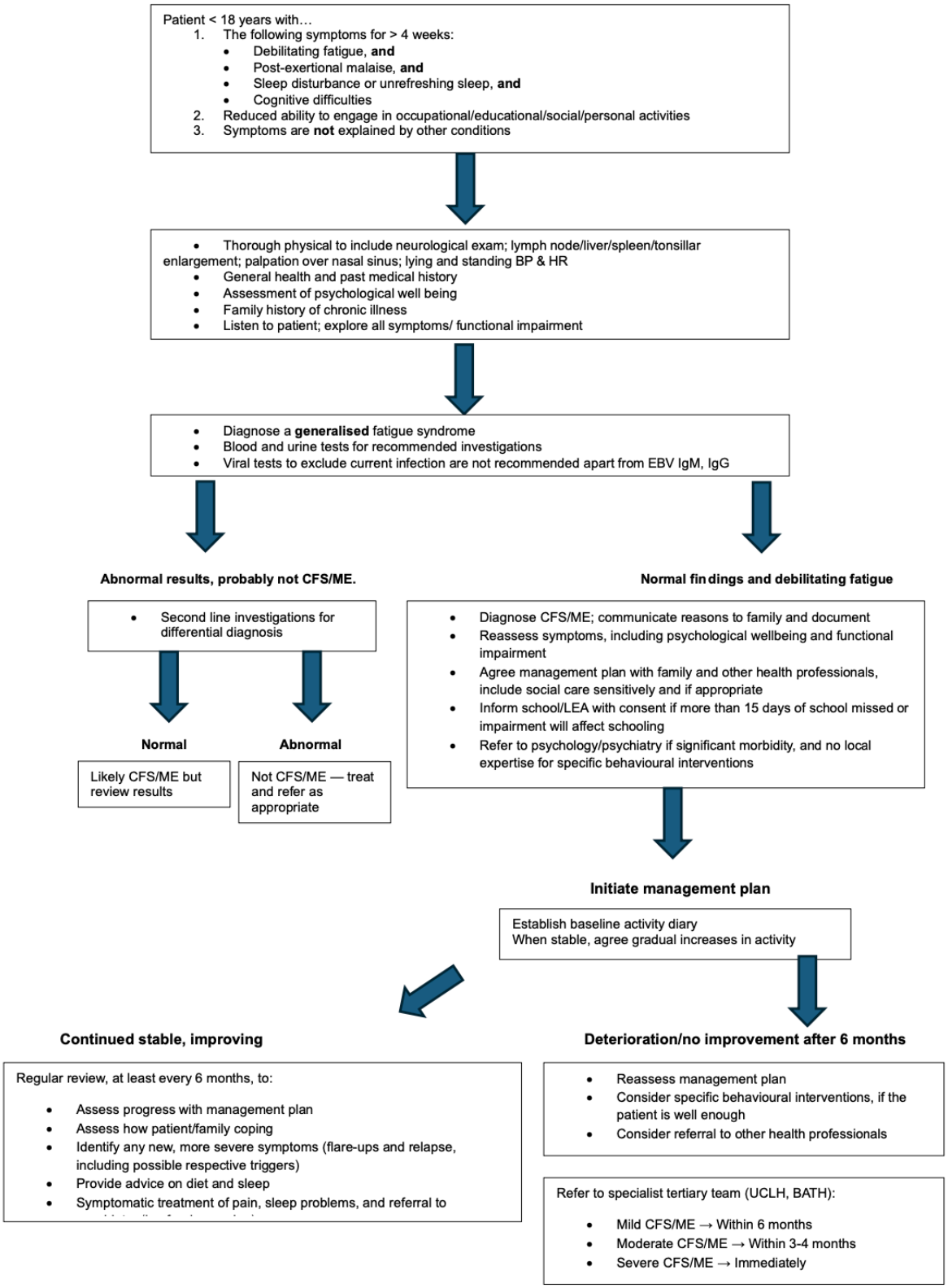
- cognitive behavioural therapy
- graded exercise therapy
- activity management programmes
- group therapy

Review

Children and young people with ME/CFS needs a review of their care and support plan at least every 6 months.

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.


Patient < 18 years with…
1. The following symptoms for > 4 weeks:
• Debilitating fatigue, and
• Post-exertional malaise, and
• Sleep disturbance or unrefreshing sleep, and
• Cognitive difficulties
2. Reduced ability to engage in occupational/educational/social/personal activities
3. Symptoms are not explained by other conditions
• 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
Normal
Abnormal
Likely CFS/ME but review results
Not CFS/ME — treat and refer as appropriate
• Diagnose CFS/ME; communicate reasons to family and document
• Reassess symptoms, including psychological wellbeing and functional impairment
• Agree management plan with family and other health professionals, include social care sensitively and if appropriate
• Inform school/LEA with consent if more than 15 days of school missed or impairment will affect schooling
• Refer to psychology/psychiatry if significant morbidity, and no local expertise for specific behavioural interventions
Initiate management plan
Establish baseline activity diary
When stable, agree gradual increases in activity
Continued stable, improving
Regular review, at least every 6 months, to:
• Assess progress with management plan
• Assess how patient/family coping
• Identify any new, more severe symptoms (flare-ups and relapse, including possible respective triggers)
• Provide advice on diet and sleep
• Symptomatic treatment of pain, sleep problems, and referral to
Deterioration/no improvement after 6 months
• Reassess management plan
• Consider specific behavioural interventions, if the patient is well enough
• Consider referral to other health professionals
Refer to specialist tertiary team (UCLH, BATH):
• Mild CFS/ME → Within 6 months
• Moderate CFS/ME → Within 3-4 months
• Severe CFS/ME → Immediately

USEFUL LINKS REGARDING SERVICE

https://bacme.info/

https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/index.asp

https://media.gosh.nhs.uk/documents/Specialist_Paediatric_CFSME_Services_England_updated_May_2015.pdf

Useful information for patients

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

Young person's guide to CFS

https://www.oxfordhealth.nhs.uk/wp-content/uploads/2019/01/Young-Persons-Guide-to-CFS-ME.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/

2. Supporting 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 Number NG206 published 29OCT 2021

https://www.nice.org.uk/guidance/ng206/chapter/Recommendations#managing-mecfs

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

3. Supporting relevant trust guidelines

Please review chronic pain guideline as there is often overlap.

2. Guideline Governance

a. Scope

This guideline is relevant to all staff caring for all children from 0-18 years old across the emergency department, inpatient ward and outpatient department.

b. Purpose

i. This guidelines aims to facilitate a common approach to the management of children. At times deviation from the guideline may be necessary, this should be documented and is the responsibility of the attending consultant.

ii. This guideline is subject to regular review to ensure ongoing evidence based practice.

c. Duties and Responsibilities

All healthcare professionals responsible for the care of all children 0-18years should be aware of practice according to this guideline.

d. Approval and Ratification

This guideline will be approved and ratified by the Paediatric Guidelines Group.

e. Dissemination and Implementation

i. This guideline will be uploaded to the trust intranet 'Paediatric Guidelines' page and thus available for common use.
ii. This guideline will be shared as part of ongoing education within the Paediatric Department for both medical and nursing staff.
iii. All members of staff are invited to attend and give comments on the guideline as part of the ratification process.

f. Review and Revision Arrangements

a. This policy will be reviewed on a 3 yearly basis by the appropriate persons.
b. If new information comes to light prior to the review date, an earlier review will be prompted.
c. Amendments to the document shall be clearly marked on the document control sheet and the updated version uploaded to the intranet. Minor amendments will be ratified through the Paediatric Guidelines Group. A minor amendment would consist of no major change in process, and includes but is not limited to, amendments to documents within the appendices.

g. Equality Impact Assessment

Background • Who was involved in the Equality Impact Assessment
Author and the supervising consultants.
Methodology • A brief account of how the likely effects of the policy was assessed (to include race and ethnic origin, disability, gender, culture, religion or belief, sexual orientation, age) • The data sources and any other information used • The consultation that was carried out (who, why and how?)
All groups of staff and patients were taken into consideration and there is no bias towards or against any particular group.
Key Findings • Describe the results of the assessment • Identify if there is adverse or a potentially adverse impacts for any equalities groups
There is no evidence of discrimination.
Conclusion • Provide a summary of the overall conclusions
There is no evidence of discrimination.
Recommendations • State recommended changes to the proposed policy as a result of the impact assessment • Where it has not been possible to amend the policy, provide the detail of any actions that have been identified • Describe the plans for reviewing the assessment
This guideline is appropriate for use.

h. Document Checklist

To be completed (electronically) and attached to any document which guides practice when submitted to the appropriate committee for approval or ratification.

Title of the document: Paediatric Chronic Fatigue Syndrome

Policy (document) Author: Aswathy Madhu, Isla Leal

Executive Director: N/A

		Yes/No/ Unsure/NA	Comments
1.	**Title**		
	Is the title clear and unambiguous?	**Y**	
	Is it clear whether the document is a guideline, policy, protocol or standard?	**Y**	
2.	**Scope/Purpose**		
	Is the target population clear and unambiguous?	**Y**	
	Is the purpose of the document clear?	**Y**	
	Are the intended outcomes described?	**Y**	
	Are the statements clear and unambiguous?	**Y**	
3.	**Development Process**		
	Is there evidence of engagement with stakeholders and users?	**Y**	**Tertiary services and network links**
	Who was engaged in a review of the document (list committees/ individuals)?	**Y**	**Paediatric guideline committee**
	Has the policy template been followed (i.e. is the format correct)?	**Y**	
4.	**Evidence Base**		
	Is the type of evidence to support the document identified explicitly?	**Y**	

		Yes/No/ Unsure/NA	Comments
	Are local/organisational supporting documents referenced?	**Y**	
5.	**Approval**		
	Does the document identify which committee/group will approve/ratify it?	**Y**	
	If appropriate, have the joint human resources/staff side committee (or equivalent) approved the document?	**N/A**	
6.	**Dissemination and Implementation**		
	Is there an outline/plan to identify how this will be done?		
	Does the plan include the necessary training/support to ensure compliance?		
7.	**Process for Monitoring Compliance**		
	Are there measurable standards or KPIs to support monitoring compliance of the document?	**N**	
8.	**Review Date**		
	Is the review date identified and is this acceptable?	**Y**	
9.	**Overall Responsibility for the Document**		
	Is it clear who will be responsible for coordinating the dissemination, implementation and review of the documentation?	**Y**	
10.	**Equality Impact Assessment (EIA)**		
	Has a suitable EIA been completed?	Y	

Committee Approval (Paediatric Guidelines Group)			
If the committee is happy to approve this document, please complete the section below, date it and return it to the Policy (document) Owner			
Name of Chair	**Alexandra Jones**	**Date**	**25/03/2026**
Ratification by Management Executive (if appropriate)			
If the Management Executive is happy to ratify this document, please complete the date of ratification below and advise the Policy (document) Owner			
Date: n/a			