Referral Support Service

Paediatrics

PA25
Chronic Fatigue Syndrome

Paediatric Normal Values (adapted from APLS)			
Age	Resp Rate	Heart Rate	Systolic BP
Neonate <4w	40-60	120-160	>60
Infant <1 y	30-40	110-160	70-90
Toddler 1-2 yrs	25-35	100-150	75-95
2-5 yrs	25-30	95-140	85-100

Definition

Chronic fatigue syndrome (CFS) also known as myalgic encephalomyelitis (ME) or CS/ME is a serious, long-term condition that affects many body systems. People with CFS are often not able to do their usual activities. People with CFS have severe debilitating fatigue which is not improved by rest and disturbed sleep

Symptoms should be present for a minimum of 4 weeks in children AND affect ability to engage in, educational, social and personal activities. The symptoms are not explained by physical or psychiatric illness.

Exclude Red Flag Symptoms

- Abnormal neurological signs
- Weight loss
- Symptoms of anxiety and/or depression
- Clinical signs of arthritis
- Skin rashes
- Localised pain waking the child at night

General Points

- Usually starts in mid-teens but can occur in primary school age.
- Commonly starts with a short or sudden illness such as ‘flu’ or glandular fever, but it can also start gradually. There may be no triggering illness.
- Diagnosis made through careful and detailed history taking and examination – it is a diagnosis of exclusion
- Process by which some children develop CFS is poorly understood – it is probably a combination of biological, psychological and social factors
- Management can be difficult
- Most children recover but may miss significant amounts of school and take months or years to regain full levels of activity
- Children and their families should have the opportunity to make informed and shared decisions about their care at every stage

Presenting Features

- Conduct a medical assessment including history, co-morbidities, physical and mental health
- Symptoms must be present for a minimum of 4 weeks;

- Debilitating fatigue that is worsened by activity and not improved by rest
- Post-exertional malaise (also known as ‘crashing’)
- Cognitive difficulties (sometimes described as ‘brain fog’), e.g. word finding difficulties, short-term memory difficulties, sensory hypersensitivity
- Sleep disturbance and/or unrefreshing sleep
- Symptoms may vary over time

Useful questions

- What is the child able to do now? How does it compare to what the child was able to do before?
- How long has the child been ill?
- Does the child feel better after sleeping or resting?
- What makes the child feel worse? What helps the child feel better?
- What symptoms keep the child from doing what he/she needs or wants to do?
- Does the child ever feel dizzy or lightheaded? Has the child been falling more often than before?
- Does the child seem to have trouble remembering or focusing on tasks?
- What happens when the child tries to do activities that used to be normal?

Associated symptoms

Type	Symptoms
Immune system	Tender lymph nodes, recurrent sore throat, flu-like symptoms, new sensitivities to food, medications and/or chemicals
Autonomic dysfunction	Dizziness, feeling faint, palpitations (including postural orthostatic tachycardia syndrome), urinary frequency, nausea, irritable bowel syndrome, exertional dyspnoea
Neuroendocrine	Difficulty regulating temperature, sweating, intolerance of heat and cold
Pain	Headaches, muscle pains, joint pains without redness, swelling or effusion.
Mental health	Anxiety, depression

Differential Diagnoses

- Long covid
- Hypothyroidism
- Anaemia
- Coeliac disease
- Mental health conditions, e.g. primary anxiety/depression, OCD, eating disorders
- Juvenile idiopathic arthritis

Investigations

Explain that while baseline tests are being performed and they are expected to be normal. The following investigations should be completed prior to diagnosis

- Coeliac screen including IgA serology in ALL children if not done in the last year
- Bloods: FBC, CRP, U&Es, LFTs, TFTs, ESR, random blood glucose, calcium, creatinine kinase, ferritin, vitamin D
- Consider serological testing if there is a history to suggest infection, particularly Epstein-Barr infection
- Urine dip: protein, blood and glucose

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

Management

- Early engagement of the family, as well as maintaining a therapeutic alliance throughout the illness, is crucial for successful implementation of the management plan
- Careful communication is key, particularly in the early stages to achieving a good outcome
- Management is under the direction of a consultant paediatrician

Sleep Management

- Providing general advice about sleep and sleep hygiene is important
- Completion of an activity diary is helpful in clarifying current sleep patterns
- The sleep-wake cycle is often reversed
- Changing to sleeping patterns should occur gradually

Rest

- Rest is an important component of the management plan
- Limiting rest periods to 30 minutes at a time may be helpful
- Start to build regular periods of rest into daily routines

Diet

- A well-balanced diet is important
- Eating regularly
- Some may benefit from 5-6 small meals a day rather than 3 large ones – this can be particularly helpful in those who have associated nausea
- Exclusion diets have not been shown to improve symptoms of CFS
- May require dietician input

Pain

- Chronic pain is a common component of CFS
- Polypharmacy and stronger analgesics often lead to side effects without alleviation of pain
- If there has been no benefit, consider weaning off regular medication and onto simple analgesia for exacerbations of pain only.

Education

- The amount of time children go to school is not the only marker of progress.
- School should not be the only activity children undertake.
- There needs to be a balance between school, home and social activities
- Many schools have very low tolerance for school absence. A letter to school explaining your working diagnosis is helpful.

Setbacks/relapses

- Setbacks and relapses are common and should be anticipated
- A setback plan should be agreed on early on in the management of CFS

Referral Information

Indications for referral to paediatrics

- If under 16 years refer to paediatrics (Dr Jo Mannion)
- If over 16 years refer to Yorkshire Fatigue Clinic

Information to include in referral letter

- History and physical exam findings
- Results of any investigations

Patient information leaflets/ PDAs

www.ActionforME.org.uk

References

- Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE guidelines NG206 Published Oct 21 [Viewed 17 Jan 2022] https://www.nice.org.uk/guidance/ng206
- Geraghty KJ, et al. The importance of accurate diagnosis of ME/CFS in children and adolescents: A commentary. Front Pediatr (2018) 6: p.435

Useful Reading

O'Sullivan, Suzanne, It's All in Your Head: Stories from the Frontline of Psychosomatic Illness, Chapter 7 June 2015, Chatto & Windus

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