

Chronic Fatigue Syndrome



What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome (CFS) is a long-term illness with a wide range of symptoms. It is characterised by extreme fatigue or tiredness that does not end with rest and cannot be explained by an underlying medical condition.

Chronic Fatigue can also be referred to as myalgic encephalomyelitis (ME) or systemic exertion intolerance disease (SEID).

CFS/ME can affect anyone, including children. It is more common in females. However, it is rare in children, according to NHS it is more likely to develop between ages 25-45.

Many adolescents have severe fatigue however the prevalence of CFS is less common. 34% to 41% of adolescents report feeling “much more tired and worn out than usual” (Wolbeek, Doormen, Kavelaars & Heijnen 2006; Collin, Norris & Nuevo, 2016). The prevalence of CFS in children and adolescents is between 0.11% and 4% (Collin *et al.*, 2016).

Factors Associated with Paediatric CFS/ME

Gender: CFS is equally common in boys and girls under the age of 13. After puberty, the prevalence increase in females but not in males. CFS is 2-3 times more common in females in older teenagers and adults.

Genetic Factors: Twin studies have shown that there are correlations between chronic fatigue and genes as these correlations are higher in children than adults. This suggests that genetics may in part be able to explain why some children get CFS earlier in life.

Infection: Infection is a known risk factor for CFS in adults and children. Viral infections such as glandular fever, bacterial infections such as pneumonia, problems with the immune system or hormone imbalances are some of the risk factors associated with CFS.

Signs & Symptoms

- Severe fatigue that can make it hard to get out of bed and do normal daily activities.
- Sleeping problems, such as not being able to fall or stay asleep, or not having a refreshing sleep
- Dizziness
- Headaches
- Stomach-aches
- Reduced concentration
- Loss of memory
- Muscle pain
- Frequent sore throat
- Multi-joint pain without redness or swelling
- Tender and swollen lymph nodes in your neck and armpits

How to Help

Part-Time Timetable

A part-time timetable is suitable for those with CFS. Attendance with the child or young person, their parents and a relevant health practitioner should be agreed in advance. This should be at a level that can be managed consistently, ideally every day at the same times, avoiding 'as and when' arrangements that are unpredictable and can cause friction. Attendance should only be increased if the child or young person believes that symptoms have improved enough to allow them to push things forward rather than fit into a pre-arranged return timetable.

<p>Cognitive Load</p>	<ol style="list-style-type: none"> 1) Tailor lessons according to student's existing knowledge and skills. Present new and complex information in small chunks. Check understanding after comprehension activities. 2) Use worked examples to teach student new content and skills. When asking student to complete a task, have a completed version of the same task alongside it for reference. 3) Cut out non-essential information. This type of information can be information that student already knows, or additional information that it not directly relevant to the lesson, or the same information presented in multiple forms. 4) Present all essential information together. 5) Simplify complex information by presenting it both verbally and visually. This strategy increases the capacity of students working memory and creates more mental space for learning.
<p>Individual Health Care Plan (IHCP)</p>	<p>Schools should develop an IHCP to support the student with CFS. The IHCP should include how to support the physical impacts of the condition and should be developed with the student and their parents. This should</p>

	<p>then be shared with all staff who work with the student so that they are aware of the circumstances and understand their needs and how to support them.</p>
<p>Designated Area to Rest</p>	<p>A designated area to rest should be provided for the student. This area should be:</p> <ul style="list-style-type: none"> • Quiet and free from interruptions • Should have privacy • There should be no expectations to study or catch up with missed work • Comfortable with seating e.g. armchairs, beanbags, or lounging beds • Cordoned off by curtains • Should have permission to listen to music or use fiddle toys
<p>Reduction in Physical Exertion</p>	<p>Schools should consider reducing the movement around the building through timetabling. They should also consider reducing the amount the child is expected to carry around in their bag, a locker could be provided. Finally, the student should be exempt from PE lessons, even if it is a part of the lesson.</p>
<p>Access to Refreshments</p>	<p>It is helpful to allow children and young people with CFS to have access to drinks and snacks, in a designated area without being challenged by staff.</p>

<p>Clear Work Expectations</p>	<p>Accessing all lesson materials can be overwhelming for a student with CFS. It is important that the student knows exactly what is expected of them. Schools should consider:</p> <ul style="list-style-type: none"> • Individual, tailored revision guides • Flexibility around hand-in dates for homework and assignments • Access to lesson plans and teacher’s notes • Regular catch up with their mentor/tutor • A procedure for signing in and out without having to attend registration
<p>Exam Considerations</p>	<p>Special arrangements for exams can be organised for students with CFS. These should be arranged with the examinations officer in a timely fashion for all exams. Some arrangements may include:</p> <ul style="list-style-type: none"> • Delayed start of the exams • Extra time • Rest breaks • A scribe • Use of a laptop • Alternative accommodation e.g. smaller room/different venue
<p>Screen Time</p>	<p>Using phones, laptops and computers can aggravate symptoms of chronic fatigue due to various reasons such as body position when spending time on computer, lighting of the electronic</p>

	<p>device and not taking breaks. To help with chronic fatigue, screen time would need to be monitored carefully and reduced where possible. If not able to reduce screen time, the screen light can be limited to blue light only.</p>
<p>Avoid Boom and Bust Cycle</p>	<p>Boom and bust cycle is a typical pattern for CFS/ME. Most people have a period in a day when they have more energy than other times. When this happens, there is a tendency to do as much as possible when energy levels are higher, which then lead to periods of fatigue and enforced rest. If the rest is only taken when the individual is exhausted, this then leads to longer time for recovery. The key point is to rest routinely and consistently before becoming exhausted.</p>

Practical Strategies for Classroom

Since ME / CFS is a complex condition that affects how students learn and interact in school, teachers and administrators may want to be innovative in designing strategies for their students with ME / CFS to promote an encouraging learning atmosphere.

Perhaps teachers and administrators want to:

- Help students with note taking.
- Give them extended time on work.
- Schedule rest breaks during lessons.
- Avoid information overload.

Clear Targets:

Small precise targets need to be clearly specified, with prompts and cues to enable the student to achieve these. These prompts and cues, often very visual, are there to help the student work through a given task. Rules need to be clear especially for these students, with positive rewards directed primarily to effort in staying on a task rather than for attainment. It is helpful if teachers try to adopt the viewpoint that they have the responsibility for communicating what the task is about and how to do it. Then, if students do not achieve, it is because the teacher has not been successful in communicating rather than the students' 'fault' for not understanding. This fundamentally non-judgemental response to failure sometimes needs to be expressed quite explicitly by the teacher: 'I'm sorry, I don't think I explained that to you very well'.

Positivity and self-esteem:

Crediting effort not 'ability', Sharing golden moments of achievement, humour, and creativity.

Providing Management and support:

Ensuring and improving the emotional climate in the classroom, using circle time and other positive self-worth activities. Ensure a good working knowledge of literacy skills develops as early as possible, Using a mentor /TA/ Peer for additional support.



Where to get help

ACTION FOR M.E.

Tel: 0117 927 9551

Email: questions@actionforme.org.uk

www.actionforme.org.uk

Action for M.E. is a Registered Charity in England and Wales No. 1036419. It provides information and support for people affected by myalgic encephalomyelitis (M.E.), sometimes diagnosed as chronic fatigue syndrome (CFS, or M.E./CFS), and their carers.

ME ASSOCIATION

Helpline: 0344 576 5326

Email: meconnect@meassociation.org.uk

www.meassociation.org.uk

The Association is a Registered Charity in England and Wales No. 801279. It provides information and support to people in the UK with ME (myalgic encephalopathy) or CFS (chronic fatigue syndrome) and their families and carers. The Association funds and supports research and provides education and training.

THE YOUNG ME SUFFERERS TRUST

Tel: 0845 003 9002

Email: via website

www.tymestrust.org

The Trust is a Registered Charity in England and Wales No. 1080985. It provides information and support for children and young people with ME and their families and professionals.

References

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Davison, K. K., Schmalz, D. L., & Downs, D. S. (2010). Hop, skip... no! Explaining adolescent girls' disinclination for physical activity. *Annals of Behavioral Medicine*, 39(3), 290-302.

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NHS website. (2020, August 10). Chronic fatigue syndrome (CFS/ME). Nhs.Uk. [https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/#:%7E:text=Causes%20of%20chronic%20fatigue%20syndrome%20\(CFS%2FME\)&text=bacterial%20infections%2C%20such%20as%20pneumonia,as%20stress%20and%20emotional%20trauma](https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/#:%7E:text=Causes%20of%20chronic%20fatigue%20syndrome%20(CFS%2FME)&text=bacterial%20infections%2C%20such%20as%20pneumonia,as%20stress%20and%20emotional%20trauma)