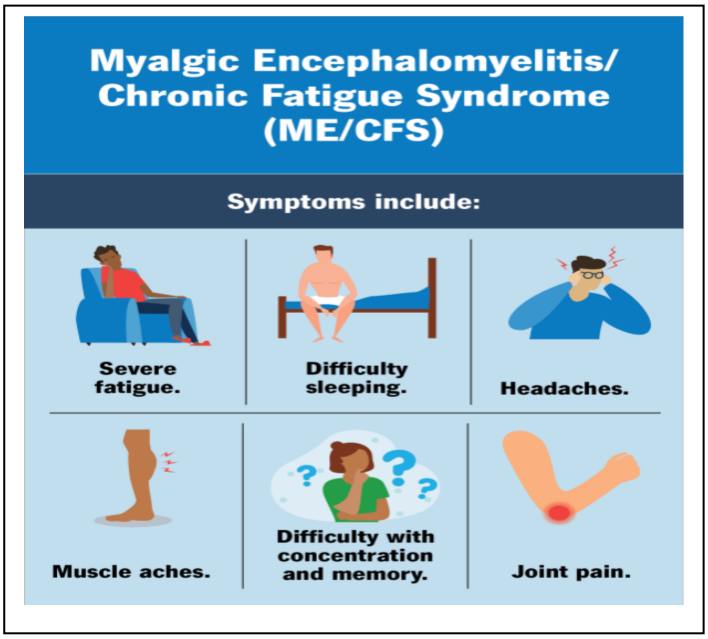
SEND Bulletin NO.6



Myalgic Encephalitis/Chronic Fatigue Syndrome (ME/CFS)

What is ME/CFS?

ME/CFS is relatively common in children, affecting at least 1% of teenagers. It is probably the largest cause of long-term absence from school. ME/CFS symptoms may include:

- Extreme fatigue after normal everyday activities
- Pain (including headaches)
- Malaise and dizziness, nausea
- Sleep disturbance
- Impaired mental functioning (poor concentration, distractibility, difficulty focussing, poor memory, ‘brain fogging’)

We usually find that children and young people with ME/CFS have only a finite amount of energy capacity and the normal “recharging of batteries” is impaired. If the amount of available energy is exceeded, then the young person experiences a ‘payback’ over the next day or two where they may feel ‘fluey’ and wiped out. This is also known as a “Boom and Bust” cycle. In our experience, young people with ME/CFS may also be more likely than those without fatigue to experience anxiety and low mood. The management of ME/CFS involves finding out how much high energy activity time a young person can spend every day, without experiencing this payback. This is called the baseline.

Energy Expenditure

There are three types of energy expenditure: physical, cognitive and emotional.

- Physical energy expenditure occurs for any activities involving mobility.
- Cognitive energy is anything to do with thinking tasks – all classroom work is high energy cognitive activity. Other high energy cognitive activity would be watching television or chatting with friends.

- Emotional energy is often easy to overlook. This includes any emotional distress, rows, anxiety and 'over-thinking' the young person experiences. Although this can be difficult to control, it needs to be factored into the available amount of energy.

Ways to help manage ME/CFS at school:

Rest breaks during school time

Some children/young people with ME/CFS benefit from regular rest breaks. These breaks should be in a quiet place, ideally away from the classroom. It would be helpful if breaks could be scheduled, especially for younger children. Other students prefer a medical timeout card which they can use in lessons if they feel they need a break. They should be allowed to leave the classroom without having to explain why. In a quiet space, e.g. the library, they should spend the time reading or listening to music or doing a downtime activity. They can be expected to return to the lesson after 10-15 minutes.

Concentration

We have found that young people with ME/CFS benefit from working in chunks of no more than 30-45 minutes; severely affected students may only be able to sustain concentration for 15 – 20 minutes. Students often have increased sensitivity to everyday sounds and are likely to be more easily distracted in the classroom environment. Students may experience 'brain fog' i.e. difficulty processing information – it can be helpful to provide written instructions and memory aids.

Exams

Young people with ME/CFS benefit from being allowed to sit exams in a room on their own, or with few other students. They should be allowed to get up and move around for timed rest breaks. We would also advise that they are allowed 25% extra time.

The above allowances will really help children and young people with ME/CFS to reach their full academic potential.

Useful Resources and Websites:

www.ruh.nhs.uk/cfs

https://meassociation.org.uk/

https://www.actionforme.org.uk/

https://bacme.info/

If you would like a particular theme covered, have any interesting information or resources which you would like to share with your colleagues via this fortnightly bulletin please e-mail me and I will share accordingly.

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Many thanks Anne