

Get to grips with ME

Chronic Fatigue Syndrome is the biggest health-related cause of long-term school absence in the UK – it's time to act

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Chronic Fatigue Syndrome (CFS), medically known as Myalgic Encephalomyelitis (ME), is the biggest health-related cause of long-term school absence in the UK. It's a condition that SEND teaching staff need to fully understand to ensure adequate support is provided and to enable students to meet their potential within learning environments.

Many ME/CFS-affected students are finding themselves expelled from school due to long-term unauthorised absence. Students are being expelled due to a lack of knowledge about the condition within the education sector.

There are a couple of key points for SEND staff to be aware of:

Firstly, there is currently no diagnostic test and so everything else must be tested for and ruled out before an ME/CFS diagnosis can be given, which usually takes about 12 months.

Also, one of the key factors in ME/CFS being a complicated and misunderstood condition is its fluctuating nature. Even if patients rest all day, doing no activity whatsoever, the symptom severity and energy level will fluctuate naturally.

Add a little bit of activity into the mix and patients have more severe fluctuations. It's difficult for patients to judge when they will feel well enough to attempt attending school, do their homework, or see their friends. More often than not, activities get cancelled.

Students may feel well enough to do several 30-minute bite-sized chunks of coursework in the morning but, by lunchtime, their symptoms will have worsened and they would be unable to do any other activity for a few hours or for the rest of the day.

ME/CFS has a spectrum of severity: mild, moderate and severe. Given the opportunity to rest and to manage their own energy levels when the symptoms start (ie. not waiting for a diagnosis) a patient could prevent the transition to a more severe form of the condition.

Even those with the mildest form of the condition lose 50% of their pre-ME/CFS level of functioning.



ME/CFS STATS

- 250,000 people living with ME/CFS in the UK
- 25,000 are children and young adults



These are the 7 key indicators for making an ME/CFS diagnosis:

1. Post-exertional malaise or symptom exacerbation

The key diagnostic feature of ME/CFS is the way in which symptoms worsen after activity is increased beyond what the patient can tolerate.

2. Exercise-induced muscle fatigue

May be accompanied by muscle pain.

3. Cognitive dysfunction

Cognitive dysfunction alone is often severe enough to cause a substantial reduction in previous levels of occupational, educational, personal and social activities.

4. Pain

That can be persistent and difficult to control. Pain is often muscular, but it can also be rheumatic or neuropathic. But pain is not always present.

5. Sleep disturbance

A non-refreshing sleep pattern that can include both hypersomnia (early in the illness) and insomnia, reversal of sleep

rhythm (especially in children), vivid dreams and 'restless legs'.

6. On-going, flu-like malaise

A general feeling of 'being unwell' that is accompanied by sore throat, tender lymph glands and problems with temperature control.

7. Autonomic symptoms

Including orthostatic intolerance. Autonomic symptoms are very common in ME/CFS, and orthostatic intolerance refers to an inability to sustain upright activity.

Whilst teachers are not responsible for diagnosing the condition, it would be hugely beneficial for staff to know the 7 key indicators. Should a student entering the prolonged testing process show signs of the above, then perhaps the school could implement an interim care plan, suitable for potential ME/CFS.

This care plan could include reduced school attendance, longer assignment deadlines, allowed to study from home. Quick and effective support is vital in the early stages of the illness to prevent developing the worst form of the condition – severe ME, in which patients are bed or house bound, often for years.