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*“ME/CFS is the most common cause of prolonged school absence due to illness.”*

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*Myalgic Encephalomyelitis, commonly known as Chronic Fatigue Syndrome, is estimated to affect around 20,000 students in Australia.*

School nurses can make a big difference in the life of a student with ME/CFS. By working in partnership with the student, their family, teaching staff, and the learning and support teams within the school, nurses are well placed to develop appropriate accommodations designed to allow students with ME/CFS to continue to attend school and connect with their peers.

## What is Myalgic Encephalomyelitis / Chronic Fatigue Syndrome?

ME/CFS is a debilitating biomedical illness affecting multiple systems. Patients commonly experience neurological symptoms, immunological dysfunction and they struggle with energy metabolism. It causes significant ill health and disability in sufferers.

Community misperception about the illness remain a challenge for sufferers. In the past, poor diagnostic criteria meant that patients with more mildly fatiguing illnesses were mis-diagnosed as having ME/CFS. Scientific advances have since unlocked a wide range of cellular functioning abnormalities in people with ME/CFS.

ME/CFS has been reported in patients younger than 10 and older than 70, and research has shown peak onsets between 11–19, and 30–39 years of age with a higher prevalence of females after puberty.

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## Supporting Students with ME/CFS in a School Environment

The following support approaches can help to alleviate ME/CFS symptoms and provide students with reassurance to reduce stress and stigma.

**Enable students to lie down** Light-headedness is very common in paediatric ME/CFS. Upright posture can aggravate other symptoms including fatigue, headache, nausea, shortness of breath and cognitive dysfunction.

### **Reduce light, noise and odours**

Place them away from chemicals or strong odours to accommodate heightened sensitivities and reduce fatigue.

### **Rest breaks help students learn**

Students with ME/CFS who are able to attend school often need regular rest breaks to cope with the long school day. Rest breaks can help them to better concentrate when they're in class, and minimise the post-exertional malaise triggered by attending school.

### **Place them away from other children with illnesses**

Immune system impairment means they are more vulnerable to other illnesses/take longer to recover.

**Validate their feelings** Students with ME/CFS are often disbelieved and labelled as malingerers. This is usually because of the prolonged time before diagnosis and the fluctuating range and severity of their symptoms. Being non-judgemental and supporting students to take the rest they need, will help them learn to avoid relapses and live within their limited energy envelope.

**Personal care plan development** Encourage students to develop a personal care plan with their doctor, which they can then discuss with you to accommodate in the school environment.

## Important ME/CFS Facts

- » **ME/CFS is most commonly preceded by a severe viral infection** such as influenza or glandular fever, and may develop gradually or very suddenly. However, an identifiable trigger is not always found.
- » **ME/CFS can lead to lifelong disability if left unmanaged.** Even mild cases can result in the loss of 50% of pre-illness functioning. Many patients are unable to work or attend school full time, and about 25% are bedbound or housebound.
- » **Pacing is currently considered to be the most effective management tool.** Pacing involves reducing the patient's physical and cognitive activity to remain within their limited energy reserves with lengthy periods of rest, to minimise post-exertional malaise (PEM) and other symptoms.
- » **There is currently no cure for ME/CFS,** however doctors may prescribe medications to help reduce symptom severity.

### ME/CFS Symptoms

The clinical hallmark of ME/CFS is post-exertional malaise (PEM). Patients are unable to produce sufficient energy on demand and even minor physical or mental exertion can result in disabling fatigue, an exacerbation of symptoms and a reduction in functioning that may continue for days, weeks or months.

#### Additional symptoms may include:

- » Cognitive impairments in concentration and information processing
- » Severe, widespread pain
- » Unrefreshing sleep and altered sleep patterns
- » Sore throat and tender lymph nodes
- » Persistent low-grade fever
- » Gastrointestinal symptoms such as irritable bowel syndrome
- » Sensitivity to light, sound, touch, odours and/or chemicals
- » Headaches
- » Facial pallor
- » Orthostatic intolerance and low blood pressure

### ME/CFS is not school refusal

Students with school refusal issues usually continue with other favoured pursuits outside school; students with ME/CFS usually want to attend school and maintain their other interests but struggle to do so due to poor physical and cognitive function.

For more information please visit:

#### School Accommodations

<https://www.emerge.org.au/your-child-or-young-person-with-me-cfs-and-school/>

#### ME/CFS Diagnosis & Management in Young People: A Primer (2017)

<http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full>

#### Emerge Australia Inc.

[www.emerge.org.au](http://www.emerge.org.au)

