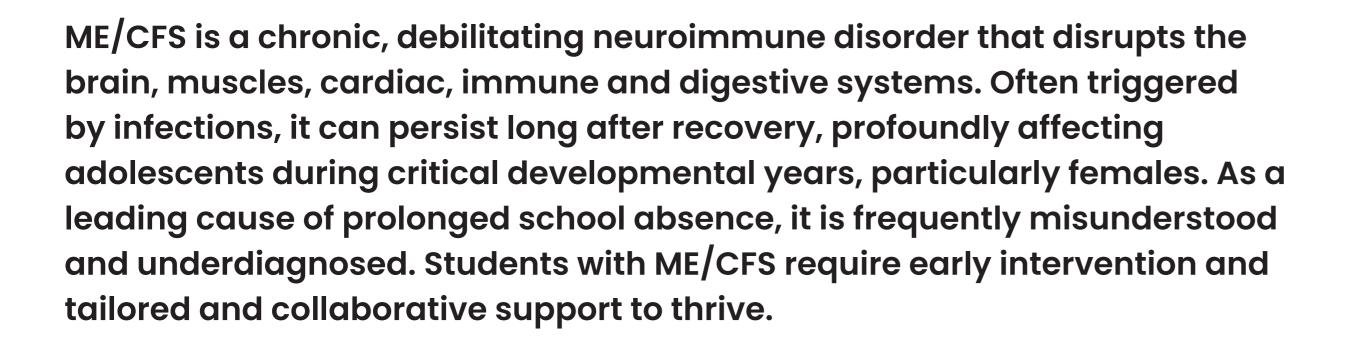
# Myalgic Encephalomyelitis, Chronic Fatigue Syndrome (ME/CFS)





#### School absence patterns

- ME/CFS causes one of the highest rates of prolonged school absences
- Attendance is often limited to one or two days per week, with some students entirely house or bed-bound







#### Health condition

- A neurological disorder affecting cognitive, physical, and sensory functions
- Severe exhaustion, described as a "battery that only charges to 10%"
- Post-exertional malaise, where minor exertion leads to crashes lasting days or weeks
- Orthostatic intolerance and neurological effects make standing or sitting upright for long difficult



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- Without accommodations, many students risk complete disconnection from education



#### Challenges for students

- Unpredictability of symptoms makes maintaining school schedules difficult
- Social isolation and stigma often lead to mental health challenges like anxiety and depression
- Fluctuating symptoms and misperceptions about laziness damage self-esteem and complicate identity development



#### **Challenges for families**

- Balancing caregiving with work and responsibilities adds enormous strain
- Families adjust routines and finances, often experiencing "third-party housebound" effects
- Accessing medical care is challenging due to a lack of specialists and outdated clinical guidelines
- Siblings may take on caregiving roles, face emotional distress, or lack of attention

### What schools should know

 ME/CFS symptoms are unpredictable; students may manage one day but need rest the next

#### Student population

Approximately **250,000 Australians have ME/CFS,** and 50% of Long Covid cases (400,000) also meet ME/CFS criteria

ME/CFS is estimated to affect around **40,000 school-aged** children

Affects **2-3 times more females,** with peak onset in adolescence (13-18 years)

An estimated **90% of cases are underdiagnosed** or misdiagnosed

"The challenges are really across all parts; it's physical, emotional, mental, and social. Because of it being a multi-system disorder, their ability to learn, to think, to communicate well, and to have the energy to maintain getting to school – it's quite the challenge"

- Early intervention, teacher awareness, and Individual Learning Plans (ILPs) are crucial to support academic success and well-being
- Adjustments like reduced workloads, flexible schedules, telepresence technology, and physical accommodations (e.g., lockers on ground floors) are critical for student success
- Peers need to know ME/CFS is a real and debilitating illness, not just tiredness, and be encouraged to maintain friendships and include affected students in activities
- Social inclusion, such as participation in events via technology, helps students feel valued and connected
- Teachers and schools need to collaborate with families and medical professionals, recognise early signs of decline, and support pacing strategies to prevent worsening symptoms



Parents of Young People with ME/CFS Australia

## Parents of Young People with ME/CFS Australia

A Facebook support group for families and carers of young people with myalgic encephalomyelitis.

> www.facebook.com/groups/ 164952131125972/