

Myalgic Encephalomyelitis, Chronic Fatigue Syndrome (ME/CFS)

MISSING
SCHOOL



ME/CFS is a chronic, debilitating neuroimmune disorder that disrupts the brain, muscles, cardiac, immune and digestive systems. Often triggered by infections, it can persist long after recovery, profoundly affecting adolescents during critical developmental years, particularly females. As a leading cause of prolonged school absence, it is frequently misunderstood and underdiagnosed. Students with ME/CFS require early intervention and tailored and collaborative support to thrive.



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



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”



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/](https://www.facebook.com/groups/164952131125972/)



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
- 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
- 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