

FACT SHEET 6: SCHOOLS & HIGHER EDUCATION

Recognising and responding to students with M.E

Educators are in a powerful position to recognise M.E in their students. Myalgic Encephalomyelitis (M.E); commonly known as 'chronic fatigue syndrome' is a medical condition that can baffle educators as symptoms can mistakenly appear as behavioural problems when, instead M.E is classified as a neurological disorder which if left unrecognised and untreated, may result in a lifelong disability.

What is M.E?

M.E. is a chronic, complex, multisystem neuro-immune disorder which has a debilitating impact on the lives of people and those who care for them. M.E. is not 'fatigue' or 'chronic fatigue'. The hallmark symptom that characterises M.E is Post Exertional Neuroimmune Exhaustion (PENE); an incapacitating feeling of 'fatigue' that incorporates the loss of cognitive and physical energy accompanied by a gamut of symptoms in multiple body systems. Activity levels can be reduced by approximately 50% or more.

Who gets M.E?

The International Consensus Primer (ICP) for Medical Practitioners (2012) estimates the number of people living with M.E to be in the vicinity of .4 – 1% of the population. This equates to 92,000 - 230,000 Australian's. It is estimated that 15% of this population have been 'diagnosed'.

Adolescents aged 12 - 17 years are more likely than younger children to develop M.E, however children as young as four years of age have developed the illness. In

adults, four times as many women as men have M.E and it is thought that oestrogen levels play a role. Onset most commonly occurs between the ages of 30 and 50. In children, equal numbers of boys and girls contract the illness up until puberty.

What causes M.E?

The cause of M.E is unknown. 80% of people with M.E contract the disease following a virus. World-wide epidemics support an infectious cause. However, it is uncertain whether the infectious agents initiated M.E or whether it was the result of an impaired immune system. A number of viruses are implicated including Epstein Barr virus, Coxiella Burnetii, Ross River virus, Tick Bite and Enterovirus. 25% of people with M.E have a genetic predisposition. 20% of people with M.E contract the disease through slow onset.

M.E symptoms in students

Symptoms progress more slowly in children than in teenagers or adults. The onset may take several months or even years in young children. In adolescents, M.E usually starts suddenly with a fever and flu-like symptoms

In addition to the hallmark symptom of **PENE**, the most prominent symptoms tend to be neurological: **headaches, cognitive impairments sleep disturbances and pain.**

Headaches: severe or chronic – often debilitating. A migraine may be accompanied by a rapid drop in temperature, shaking, vomiting, diarrhoea and severe weakness.

Cognitive Impairments: difficulty focusing eyes and reading are common. Children may become dyslexic, which may only be evident when fatigued. Slow processing of information makes it difficult to follow auditory instructions or take notes. All cognitive impairments worsen with physical, mental and emotional exertion. Young people will not be able to maintain a full school program.

Sleep disturbances: prolonged sleep, chaotic sleeping patterns, vivid dreams/nightmares, unrefreshed sleep.

Pain - may seem erratic and migrates quickly.

Young people with M.E are often caught in a push/crash cycle response to their symptoms. When the severity level of their symptoms is low, they feel good and push themselves. Once they exceed their energy limits, their symptoms intensify, causing them to 'crash'; experiencing PENE. In young people this cycle is exacerbated with attempts to keep up with peers.

It is important to listen to what the student has to say about the severity of his/her symptoms

The severity of symptoms varies. Some children are severely disabled and bedridden.

Others go to school part time whilst some can manage full time. Most children fall between the two ends of this spectrum. Remissions and relapses are common. *Relapses may be caused by over-exertion or by other infectious illnesses.* Over time, slow improvement is likely, especially in the first four years. Recovery rates are uncertain but rates of up to 40% have been reported. Children whose health improves to near pre-illness levels are likely to find that they still need more rest than their peers.

How is M.E diagnosed?

Diagnosing M.E is difficult because there is no biomarker. It remains a diagnosis by 'exclusion'. This involves medical tests to exclude other medical conditions.

The M.E ICP (2012) identifies four criteria for diagnosis:

1. Compulsory: Post Exertional Neuroimmune Exhaustion (PENE) - A person with M.E experiences a pathological slow recovery of mental and physical function ranging between 24 hours and four days post physical and /or mental exertion.
2. Neurological Impairments – At least one symptom from three of the following four symptom categories:
 - Neurocognitive impairments
 - Pain
 - Sleep disturbance
 - Neurosensory, perceptual and motor disturbances
3. Immune, Gastro-intestinal and genitourinary impairments – at least one symptom from three of the following five symptom categories:
 - Flu like symptoms
 - Susceptibility to viral infections
 - Gastro-intestinal tract
 - Genitourinary
 - Sensitivities to food, medications, odours and chemicals.
4. Energy metabolism/ion transportation impairments – at least one symptom from the following
 - Cardiovascular i.e. orthostatic intolerance
 - Respiratory
 - Loss of thermostatic stability
 - Intolerance of extremes of temperatures

M.E and mental health

When students attend class they usually look well. This outwardly normal appearance may lead to the accusation of School Avoidance Behaviour (school phobia), or labelled as 'lazy', a 'malingerer' or the citing of a parent for Munchausen's syndrome by proxy. Educators need to be aware that severity of symptoms vary rapidly and dramatically hour to hour, day by day.

What may confuse clinicians and educators furthermore is that some students with M.E may develop *reactive depression* due to the disabling impact of M.E on their lives. Students can appear depressed because they are lethargic. **This should not be confused with primary depression.** The incidence of depression and anxiety in M.E is no different to any other chronic disease; estimated at 30 - 40% of this cohort. (Thieme et al, 2004; Hickie et al, 1990; Fiedler et al, 1996). The incidence of depression (and anxiety) is less in students who are well supported and understood by family, educators GP's and peers.

Anxiety in students with M.E can be confused with Orthostatic Intolerance; severe blood pressure changes upon standing or standing for too long. This has the effect of a racing heart rhythm which can be misinterpreted as a 'panic attack'.

In addition to the physical and cognitive limitations of M.E, a student can experience a huge sense of loss and isolation which may materialise in grief, depression and anxiety. For a clinician or educator it then becomes difficult to isolate M.E from mental illness. The stigma confusing M.E with a mental illness exacerbates the stress of living with M.E.

Dr Eleanor Stein; leading psychiatrist, clearly distinguishes M.E from psychiatric disorders in her paper: 'Assessment and treatment of patients with ME/CFS: Clinical Guidelines for Psychiatrists'(2005). This

difference is further supported by the Centres for Disease Control and prevention (CDC) that recognises M.E as a physical; not psychological or psychiatric disorder. The ICP differentiates M.E from depression through a barrage of medical tests. A distinguishing question to ask a student is "if you were well what would you do?" Most students with M.E will be able to provide a raft of ideas. Such a response is very different for a student diagnosed with depression.

What are educator's responsibilities to students with M.E?

The laws governing teacher's responsibilities to students with M.E are the Commonwealth Disability Discrimination Act 1992, State Equal Opportunity Acts and the Victorian Education and Training Reform Act 2006 and equivalent State Laws.

Under Section 32 of the Disability Discrimination Act 1992, education providers must comply with the Disability Standards for Education. To comply, an education provider must make 'reasonable adjustments' to accommodate a student with a disability. An adjustment is considered reasonable if it reflects a balance between the need for change with the expense of effort required across all parties including: the student with the disability, the education provider, staff and other students.

Reasonable adjustments for schools

Students with M.E have a better outcome if they incorporate 'pacing' into their school routine. Pacing involves understanding your energy limits and adapting to them. It offers the possibility of a more stable and predictable daily pattern rather than the push/crash cycle.

Depending on the severity level of symptoms a school can incorporate the following reasonable adjustments to optimise learning outcomes.

Incorporation of a 'Pacing Plan' as part of the students personal learning plan. A Pacing Plan recognises the limitations of a student's ability/disability levels and monitors all activities to ensure students remain within their 'energy limits'. Activities will need to be interspersed with rest, adopt energy saving practices and all mental and physical activity needs to be curbed at the slightest sign of overexertion.

Allowances for part-time study/ reduced school hours, distance education, home tutoring, a combination of the above or postponement of education until the student is well enough to resume studies. Students with M.E should never be forced to attend school; doing so can cause severe relapses.

Curriculum changes may be required. Often students with M.E are encouraged to attempt **core subjects** however, this strategy conflicts with neurocognitive setbacks experienced by students with M.E including: short term memory problems, word finding difficulties, inability to calculate numbers, disorientation, information processing difficulties, categorising words/word retrieval, inability to comprehend what is read/ overload phenomena. The best predictor for functional outcomes with students with mecs is continued engagement with education; 'emotional wellbeing' being of paramount importance. Students are encouraged to attempt subjects they enjoy. Most will require dispensation from sport due to the risk of PENE.

Students may qualify for government grants seeking additional classroom assistance such as: a scribe, lap-top, magnifier to increase print size, books on audio tape, twin sets of books (home/school) provision of written work in electronic format so they can reproduce the material into larger print or alternative colour print. Some students can perform cognitive tasks better and for longer when lying in a semi recumbent or recliner type chair as this

reduces cardiac difficulties and increases blood flow to the brain. Others may require oxygen therapy. Taxi vouchers will help to minimise the need for public transport or having to walk to school.

Students with noise sensitivities may find assemblies exacerbate their symptoms. Those with orthostatic intolerance (approximately 80%) may be unable to stand still even for very short periods.

Teaching Tips

For neuro-cognitive problems teachers can incorporate a variety of teaching methods such as, videos, handouts, study sheets, email communication, tape recorded lessons and powerpoint presentations. Book and reading lists, chapter outlines and study guides can be provided before the semester commences. Students can maintain better focus when seated closer to the speaker. When talking to the student rephrase important points, speak clearly, face the student and use simple language. Verbalise points that are written onto boards and use a microphone in large venues. The student may find it difficult to participate in discussions, conduct presentations or read aloud.

School/campus environment

Some students may use a motorised wheelchair on some days even though they have normal range of motion. When possible have classes scheduled downstairs if there are no lifts and allow unrestricted access to a *quiet room* for rests.

Chemical sensitivities can be common and schools can adopt chemical free classrooms. Visual disturbances can be caused by fluorescent lighting and glare. Natural lighting or incandescent are less problematic. Some may need to wear dark glasses if they have a light sensitivity.

Assignments, Tasks, Tests and Exams

Instructions may need to be repeated and/or put in writing. Deadlines will need to be flexible.

Tests and personalised exams should include extra time with rest breaks or a split exam over more than two days. This will take into account the pathological slow recovery of both mental and physical function, (1-4 days after physical or mental activity). Time may need to be allocated for food, drink or medication. Some may require oral exams or a quiet private room. Test questions may need to be reworded to allow for clarification of understanding. Multiple choice questions can pose problems - particularly when there are only slight variations in the answer options. Jargon should be avoided unless it is crucial to the subject theory. Those in year 11 and 12 will need to apply early in the school year for Special Provision in subject assessment.

Helping students emotionally

Students with M.E experience a range of conflicting emotions. Often they are disbelieved and labelled as lazy or malingerers. This is exacerbated by the fluctuating range and severity of symptoms. Needing to be accepted by their peers often pushes the student beyond their energy limits resulting in a push/crash cycle of symptom management to their detriment.

Accepting and being non-judgemental of a student with M.E will help them come to terms with their illness.

The following grief cycle is typical in young people with M.E and includes:

Denial - the belief that they are not sick and the need to be like everyone else.

Isolation – the realisation that they cannot keep up with their peers. Re-evaluating lifestyle, withdrawing from friends and peers.

Grief/Loss – grieving what they are no longer able to do

Depression/Anxiety—Frustration and lack of hope. A growing sense of doom/never improving.

Resilience/acceptance—I am who/what I am. I will do what I can. My illness has taught me special things. I will be a different person. A renewed sense of hope and belief.

A counsellor can help a student deal with the grief and loss associated with having M.E. Preferably, they will have an understanding of M.E.

The more a student is supported by their, school, family, peers and community the greater the chance of a better outcome for students in general.

References available upon request.

APPENDIX 1 – Dr Bell's Disability Scale

CFS Disability Scale

100	No symptoms at rest. No symptoms with exercise; normal overall activity level; able to work full-time without difficulty.
90	No symptoms at rest; mild symptoms with activity; normal overall activity level; able to work full-time without difficulty.
80	Mild symptoms at rest, symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.
70	Mild symptoms at rest; some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full-time with difficulty.
60	Mild to moderate symptoms at rest; daily activity limitation clearly noted. Overall functioning 70%-90%. Unable to work full-time in jobs requiring physical labour, but able to work full-time in light activities if hours flexible.
50	Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duty or desk work 4-5 hours a day, but requires rest periods.
40	Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 50%-70% of expected. Not confined to house. Unable to perform strenuous duties; able to perform light duty or desk work 3-4 hours a day, but requires rest periods
30	Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform desk work 2-3 hours a day, but requires rest periods
20	Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 30%-50% of expected. Unable to leave house except rarely; confined to bed most of day; unable to concentrate for more than 1 hour a day.
10	Severe symptoms at rest; bedridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.
0	Severe symptoms on a continuous basis; bedridden constantly; unable to care for self.

REFERENCE: 'The Doctor's Guide to Chronic Fatigue Syndrome' by David S Bell.

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