



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



ME/CFS Entry

Organisations who wrote / approved the information

ME/CFS Australia (Victoria)

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A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) is a complex illness that affects many parts of the body, particularly the nervous, immune and endocrine (hormonal) systems. It can cause marked disruption to all aspects of a child's life.

Every child is affected differently, depending on their particular combination of symptoms and the overall severity of their condition.

Symptoms

ME/CFS can cause a vast array of symptoms of varying severity.

Each child's combination of symptoms and symptom severity is unique, as is their overall illness severity.

The symptoms fluctuate in severity, usually from day to day, but sometimes from hour to hour.

The symptoms may also vary over the course of the illness. For example, flu-like symptoms tend to be more common in the early stages of the illness.

Effect of activity and post-exertional malaise

The symptoms of ME/CFS typically worsen with physical or mental activity. The amount of activity needed to worsen symptoms varies from child to child, and from day to day, but it can be minimal.

In addition, children with ME/CFS take much longer to recover from activity than healthy children, at least a day and often substantially more.

If a child exceeds their 'activity limits', they may develop 'post-exertional malaise or fatigue' and may even 'crash'.

Post-exertional fatigue is a complete lack of mental and physical stamina, extreme muscle and cognitive fatigue, muscle pain, and a worsening of the child's usual symptoms.

If a child over-exerts themselves to the point of 'post-exertional malaise', the time needed to recover from the exertion may be extreme, ie weeks or months.

Persistent or recurring unexplained fatigue

The fatigue of ME/CFS is an overwhelming physical and mental exhaustion that does not readily improve with rest. It may be accompanied by debilitating weakness, heaviness, malaise, light-headedness or sleepiness.

It is not like the 'tiredness' that healthy people experience after strenuous exercise or a hard day's work. It is also not the 'chronic fatigue' that many people with chronic illnesses experience.

ME/CFS fatigue reduces a child's activity levels by at least 50% and often more.

Neurological and cognitive problems

The neurological and cognitive symptoms can be extensive, and may include:

- difficulty finding words
- short-term memory and concentration problems
- problems processing and recalling information
- difficulty making decisions
- difficulty reading and writing
- difficulty with mathematics
- intermittent dyslexia
- inability to do more than one task at a time
- confusion
- disorientation
- poor balance
- clumsiness
- muscle weakness
- problems focusing the eyes
- ringing in the ears
- increased sensitivity to light and sound.

Other symptoms

Sleep dysfunction, including unrefreshing sleep, excessive sleep and disturbed sleep rhythms.

Pain, including headaches, muscle and joint pain that may be widespread and migratory, and widespread tenderness.

Symptoms of autonomic nervous system dysfunction, including light-headedness on standing, nausea, abdominal cramps, diarrhoea and/or constipation, urinary frequency, extreme pallor, palpitation, and breathlessness with exertion.

Symptoms of neuro-endocrine system dysfunction, including fluctuating or low body temperature, feelings of feverishness, episodes of sweating, cold extremities, flushing, anxiety and panic attacks, worsening of symptoms when stressed, and marked changes in weight.

Symptoms of immune system dysfunction, including tender lymph glands, recurrent sore throats, general malaise, flu-like feelings, allergies, and food, chemical and medicinal sensitivities.

Causes

ME/CFS most commonly develops after an acute infection, such as a flu-like illness, an upper respiratory infection, glandular fever or Ross River fever.

Less commonly, it may be triggered by exposure to chemicals, heavy metals or environmental pollutants, an injury such as major surgery or a serious accident, immunisation, or an anaesthetic.

ME/CFS may also develop gradually without any identifiable trigger. This insidious onset appears to be the way many children develop the condition.

Although a trigger can sometimes be identified, it is probably not the only factor that leads to the development of ME/CFS. More likely, it is the combined effect of several factors, including a trigger and a genetic predisposition, that results in a child developing ME/CFS.

Diagnosis

There is no simple diagnostic test for ME/CFS.

A diagnosis is made only if the child has a specific combination of the symptoms discussed above, and comprehensive tests and investigations have shown that the child does not have any known illness associated with those symptoms.

Who gets ME/CFS?

ME/CFS affects people of all ages, including very young children.

Children tend to develop ME/CFS after the age of 8, and most commonly around the onset of puberty.

The Royal Australasian College of Physicians estimates that ME/CFS affects between 0.2% and 0.7% of the population. Assuming the rate is the same in children, this means that approximately 1100–3750 students in Victorian Government schools suffer from the condition. This equates to 1 child in every 143–488 students (based on 2006 enrolment figures of 537,646 students).

2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

At this stage, there is no cure and no universally recognised treatment for ME/CFS.

Treatment aims to improve the child's health and quality of life by alleviating their symptoms and reducing the severity of their post-exertional malaise as much as possible.

Many people with ME/CFS improve slowly over a period of months or years. Some people recover well, but many remain severely affected by the condition, and some even deteriorate. Less than 10% of people regain their previous level of health.

Relapses and remissions are common.

Individualised treatment plan

It is widely recommended that each child have their own individualised treatment plan drawn up by a medical practitioner in close cooperation with the child and their family.

The plan is tailored to the child's symptoms, total illness severity, illness history, developmental age and personal circumstances.

It is also flexible enough to accommodate the fluctuations in the child's symptoms and activity limits, so the plan can be adjusted depending on how the child is feeling at the time.

The treatment plan is designed to help the child and their family deal with the unpredictable relapsing and remitting nature of ME/CFS, so the child can lead as normal a life as possible without aggravating their symptoms.

The plan may include

- pacing (see below)
- coping strategies, including lifestyle and environmental changes, aimed at facilitating healing and removing factors known to aggravate the child's symptoms
- medicinal treatments to alleviate specific symptoms
- other treatments aimed at treating the possible causes of the condition, such as antibiotics, antiviral medicines and essential fatty acids.

Pacing

Pacing is the most important tool for managing ME/CFS, especially post-exertional malaise.

Pacing is essentially 'working' within the child's activity limits to prevent any over-exertion that might aggravate their symptoms and precipitate post-exertional malaise. It aims to maximise the child's activity levels without worsening their illness.

Pacing requires the child

- to consciously schedule and monitor their activity throughout the day to ensure that they keep within their limits for that day
- to intersperse periods of activity with periods of rest
- to adopt energy-saving practices
- to stop mental and physical activity as soon as they start to feel any signs of reaching their activity limit.

There is evidence that living within their activity limits can lead to an improvement in the child's condition.

Conversely, going beyond their activity limits too often is thought to delay recovery and lead to a long-term worsening of the child's condition.

B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

The debilitating chronic fatigue and post-exertional malaise of ME/CFS means that children with ME/CFS have little energy, are chronically tired and needs lots of rest. As a result, their activity levels are reduced by at least 50% and often more.

In the early stages of the illness, children with ME/CFS need lots of sleep. It is not uncommon for them to spend 18 or more hours in bed sleeping, and the rest of the day lying on the couch.

Even 'minor' activities, such as climbing stairs, walking, sitting upright for long periods, long conversations and mental activity, can lead to exhaustion in a child with ME/CFS.

Once exhausted, a child with ME/CFS often finds it difficult to think and concentrate, so they may have difficulty following conversations or understanding simple instructions.

Over time, children with ME/CFS may become better at knowing how much they can do without over-exerting themselves. However, the desire to be 'a normal kid' when they feel better means that they often 'overdo it'. If they push themselves too far beyond their limits, they may take weeks or months to recover.

The unpredictable day-to-day and hour-to-hour fluctuations in symptoms add to the frustrations of living with ME/CFS.

The fluctuations also make it difficult for people to appreciate how sick the child really is, because they usually only see the child when they are 'out and about' on their good days. They rarely see them when they are confined to bed on their bad days.

Having to deal with the scepticism that results from people's lack of understanding of ME/CFS and only seeing them when they are at their best can markedly undermine the child's self esteem and general well-being.

The restrictions imposed by ME/CFS mean that the child misses out on all aspects of life, ie family, social and recreational life as well as school life. This can have a devastating impact on their social development.

Continued on page 6

2. Effects on those close to the child/young person

Having a sick child in the family is stressful and frustrating for everyone, particularly when the illness has no cure and is as debilitating as ME/CFS can be.

Siblings may become resentful if they feel they are being excluded and deprived as a result of the attention given to the sick child.

Managing a child with ME/CFS is a family affair in which parents usually play the primary steering role, even if the child is older.

The steering role involves not only managing the child's illness, but also managing other people's reactions to their illness, and the mistrust and scepticism often directed at ME/CFS.

3. "In Their Shoes" - stories from children/young people with the condition

Going home I didn't feel quite right. Something was wrong. Almost overnight my sleep patterns went haywire. The muscle fatigue which had plagued me for so many years returned. I had headaches and pains, especially in my legs. I'd taken a massive step backwards and all the hard work and progress I'd made in the last 4 months was lost. Lessons learned the hard way – never underestimate ME/CFS."

Alistair Lynch - AFL Footballer (From his book, Taking Nothing for Granted)

Young people's experiences of ME/CFS

What do you think is the worst thing about having ME/CFS?

"There is a whole period of grief and loss that you go through because, effectively, you've lost part of your life; I think that is a big thing to deal with."

What do you miss?

"I miss being a teenager. I miss being able to go to school and I miss being able to dance; I miss being the person who was confident and ran around doing everything and was always smiling."

Sacha, Age 17

"I have found the isolation that is associated with months and even years of being housebound and being unable to enjoy social contact with other teenagers particularly trying."

"...Of great reassurance to me when unable to do school work was the advice of my school headmistress who said, 'Education does not only occur from nine 'til three between the walls of a classroom.'"

Alison, Age 19

C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

Introduction

ME/CFS usually leads to a marked deterioration in the child's school attendance and performance. As a result, children with ME/CFS often need special arrangements for attending school and completing their class work, assignments and exams.

A report by the UK Department of Health states that children with moderate-severe ME/CFS should not be expected to attend school, as doing so can cause severe relapses of their condition. Such children need home tutoring or distance (correspondence) learning.

In terms of performance, maths often causes the most problems because of the logical and sequential nature of the subject. However, difficulties with reading comprehension and writing are also common.

Inform school staff

All school staff involved with the child should understand the general nature of ME/CFS and the limitations it can place on a child, particularly in relation to mental and physical activity, the need for rest, and the dangers of over-exertion.

Staff should also have an up-to-date understanding of the child's symptoms, what they can and cannot do, and how much activity they can manage safely (recognising that this varies from day to day).

Develop a realistic schooling plan

The child's teachers and School Wellbeing Coordinator should work with the child and their family to develop a realistic plan for the child's schooling.

The plan should

- be based on the child's individualised treatment plan
- provide realistic goals
- be flexible
- recognise that educational opportunities are much broader and flexible now than they were in the past
- recognise that the child is the best judge of their capabilities at the time.

Schooling options include

- full-time study with reduced physical activity (eg, no PE)
- part-time study with reduced hours (eg, part days and/or a reduced number of days) and a reduced workload
- distance (correspondence) education
- home schooling
- a combination of the above
- postponing of formal education until the student is well enough to resume their studies.

Tips for helping students with their academic needs

Give the child clear directions as to what work is high priority and what is optional, recognising that the child must make the ultimate decision about what they do and when they do it, depending on how they feel.

Consider the likely impact of the school environment on the child and minimise that impact if possible. For example, schedule their classes on the ground floor rather than the first floor, so they don't have to waste precious energy going up and down stairs.

Continued on page 8

Give the child unrestricted access to the sick bay for rests.

Consider giving the child two sets of texts — one for school and one for home — so they don't have to carry heavy bags to and from school.

Tape important lessons and/or provide class notes for the child.

Provide whole lessons for the child to complete at home.

Consider having a designated place where the child's teachers can leave work for the child, which the family collects and returns when completed. This could also be the place where any communications between school and home are exchanged.

Consider nominating a staff member, such as the Year Coordinator or Welfare Coordinator, to be the child's contact person, and encourage all information and negotiations to be relayed through that person.

Work out the best way to assess the child's academic progress.

Tips for helping students with their social and psychological needs

Trust the child, and be supportive and non-judgemental at all times.

If the child is not attending school regularly, keep in contact with them by email and/or telephone.

Talk with the child about their experiences of ME/CFS and its impact, and ask them what can be done to help them.

Encourage the child to stay at school during breaks, so they can socialise with their friends (in a quiet and comfortable place if necessary).

Be aware that the child is missing out on their family, social and recreational life as well as their school life.

Be aware that other students may need help to understand ME/CFS and its impact.

Encourage the child to access support networks, such as the ME/CFS Society, so they can make contact with other ME/CFS sufferers of their own age.

2. Link(s) to useful other online resources for schools on strategies in responding to a child/young person with this condition

Paediatric case definition: <http://www.iacfsme.org/Portals/0/pdf/pediatriccasedefinitionshort.pdf>

Education Department: www.vcaa.vic.edu.au/vce/exams/special_provisions/schoolassess.html

Alison Hunter Memorial Foundation Education Guidelines: www.ahmf.org

D: FURTHER INFORMATION

1. Organisations, including services and resources available

ME/CFS Australia (Victoria)

21-23 Livingstone Close
Burwood, Vic 3125

Ph: 03) 9888 8991

www.mecfs-vic.org.au

admin@mecfs-vic.org.au

ME/CFS Australia

www.mecfs.org.au

mecfs@mecfs.org.au

Reading, including links to downloadable documents (as above)

Practitioner guidelines <http://www.mecfs.org.au/?q=node/33>

Websites

ME/CFS Australia (Victoria) www.mecfs-vic.org.au

ME/CFS Australia www.mecfs.org.au

ME/CFS Society (SA) <http://sacfs.asn.au/>

ACT ME/CFS Society <http://www.mecfscanberra.org.au>