

ME North East
Bullion Hall
South Approach
Chester le Street
Co Durham
DH2 2ES

Tel: 0191 389 2222/388 4228

E-mail:
info@menortheast.org

Website:
www.menortheast.org

Facebook:
www.facebook.com/MENorthEast



Guide to ME

Help and advice for teachers



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ME is an illness and stands for Myalgic Encephalopathy – which means muscle (myalgic) and brain (encephalitic) symptoms. ME is also known as Chronic Fatigue Syndrome (CFS).

How does ME/CFS start?

Often it will start after an ordinary viral infection – flu, chicken-pox, glandular fever. It is possible for an apparently healthy person to come down with a viral infection, and develop full-blown ME immediately. In other cases, there may be no obvious viral ‘trigger’ at all, and the person may ‘slide’ into the illness over a period of months or even years.

What are the symptoms?

As its name suggests, ME mainly affects the muscles and the brain: muscle symptoms include severe fatigue on exercise, muscle pain and spasms. It’s important to appreciate that the kind of fatigue experienced by many ME sufferers is quite different from the straightforward ‘tiredness’ most normal people experience. ME sufferers have likened the fatigue to being ‘totally drained’ of energy and unlike many other illnesses, exercise may make things worse. Any physical activity – even walking up or down stairs – may cause pain and discomfort, and even cause a major relapse. Sometimes, you will see ME sufferers apparently able to do physical things, yet complaining of terrible fatigue and muscle problems. What you *haven’t* seen is the price they pay afterwards for their physical exertion – perhaps days in bed recovering. It is as though their muscles have a limited ‘energy supply’. When this runs out, the muscles stop functioning and need time to ‘recharge’.

The brain symptoms experienced by some ME sufferers include: headaches, dizziness, ‘swimmy’ feelings and perhaps most difficult of all to handle, loss of concentration and short-term memory. Some ME sufferers will often forget things you have just told them, and will find it hard to take in new information – especially if it’s complicated. These problems will tend to be worse when fatigued, and mental exertion as well as physical, may be exhausting for people with ME.

These are not the only symptoms experienced in ME. Sufferers will often feel ‘ill all over’, and experience many flu-like symptoms; nausea, shivering, fever and aching joints, contact with viruses can have a severe effect for days. They may be overly sensitive to heat and cold. Digestive problems are also common.

ME is a very variable illness and it may vary from week to week, day to day, or even hour to hour. So don’t be surprised if one week an ME sufferer is ‘up’ and doing normal things, and the next they’re in bed most of the time. Also, like any illness, it affects everyone in different ways.

How it affects

- ◇ nausea
- ◇ IBS symptoms
- ◇ concentration problems
- ◇ memory problems
- ◇ muddling words
- ◇ difficulty learning
- ◇ headaches
- ◇ persistent fatigue caused by mental effort
- ◇ persistent fatigue caused by physical effort
- ◇ over responsive to viruses, such as colds; can be unwell for days
- ◇ problems sleeping
- ◇ painful/weak muscles and joints
- ◇ sore throat
- ◇ light, sound, touch sensitivity
- ◇ hot and cold sensitivity
- ◇ Dizziness

How should I deal with a person with ME/CFS?

The most important thing to remember, is that ME sufferers get very tired, and it may be disastrous for them not to rest when they need to, and for as long as they need to. Also, ‘normal’ activities like conversation, which require very little energy from a healthy person, may be very exhausting for someone with ME. If an ME sufferer tells you they have to rest, or they cannot carry on talking to you, respect their need – it is absolutely necessary.

Sometimes, an ME sufferer may seem to not be taking in what you are saying to them. These problems of concentration and memory are symptoms of the illness, and will vary according to how ill the person is feeling, and how exhausted they are. Slow down your conversation, and if necessary say or explain things to the sufferer a second time, without being patronising.

What can I do to help?

- ◇ Talk to them in private and ask them what they would like you to do.
- ◇ They may want rest breaks half way through the lesson.
- ◇ Enable them to use a quiet room during breaks.
- ◇ Don’t patronise them, they are still intelligent but may require new techniques to help with concentration, learning and memory, if these symptoms affect them.
- ◇ Don’t draw attention to their illness in class.
- ◇ Notice signs of tiredness, such as paleness or dark eye circles and offer them a break.
- ◇ Do not give them additional stress, allow them plenty of time for assignments.
- ◇ Offer to email them work when they are unable to attend school.
- ◇ Make them feel included.