

**Information  
for  
Parents  
and  
Teaching Staff  
Involved  
with  
Children who have  
CFS/ME**

# Symptoms of CFS/ME

Symptoms vary between individuals and fluctuate in individuals. There is a wide variation in the severity of the condition. The most common features are-

- Unexplained, ongoing chronic fatigue that is of new or definite onset (not lifelong). This fatigue is not caused by ongoing exercise and is not greatly helped by rest. It results in large and varying reduction in educational, social or personal activities.
- Muscular pain (without joint swelling or redness). The pain is often severe.
- Muscle weakness; can be severe, affecting standing, grip, etc.
- Difficulty with short-term memory or concentration. This is often known as 'brain fog'.
- Difficulties with speaking and writing skills.
- Headaches of a new type, pattern or severity, often not helped by medication.
- Marked paleness when tired.
- Disturbed sleeping patterns, with unrefreshing sleep, too much sleep or very little sleep.
- Sore throat.
- Tender lymph nodes, e.g. in armpits or neck.
- Very sensitive to sound, light, and smell.
- Chest and abdominal pain, which can be severe.

- Loss of appetite, nausea, bloating, constipation, diarrhoea.
- Sudden intolerance to normal foods.
- Hyperventilation. (Breathing too fast and/or not deeply enough.)
- Feeling unwell after exercise. This lasts more than 24 hours, but may not start straight away.
- Poor circulation and control of body temperature. May be very hot or very cold, whatever the weather.
- Disturbance of balance, which can lead to unsteadiness and falls.
- Sore, red eyes.

## Cause of CFS/ME

This is unknown, but may involve viral or other infections, immunisations, acute stress caused by specific trauma, pesticides or other environmental agents. The onset can be sudden or gradual. Diagnosis is reached by a process of elimination as there is no diagnostic test as yet, though taking a careful history should raise the possibility of CFS/ME.

# Treatment & Outlook

There are no universally accepted treatments for CFS/ME and some are not suitable for all, e.g. Graded Exercise and Cognitive Behaviour Therapy. Large numbers of people find that Pacing is the most appropriate management approach. Many people try Complementary Therapies and some individuals find that these relieve some symptoms. The outlook for the condition is unpredictable, with some people improving within a year, whilst others can be unwell/disabled for long spells.

*"Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning...A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician." (1)*

# Factors to Consider when Educating a Child with CFS/ME.

## Overview

- CFS/ME is thought to be the cause of the largest amount of long-term absence from school.
- Flexibility in education and adaptation to the severity of the condition are essential.
- Sometimes education may need to cease temporarily if the child is very unwell.
- When a child is absent for a prolonged period, referral should be made to the Hospital and Outreach Teaching Service. The Outreach Team and Community Child Health Service jointly assess referrals and, where appropriate, outreach tuition will be provided to support the work of the school.

## Planning education

- Teaching sessions at home will probably need to be kept short and subject to regular review.
- A reduced timetable/homework may be required for children able to attend school.

- Education may need to be flexible; some children may benefit from a more general education or from concentrating on individual subjects if that is what suits their current condition.
- Regular review by staff and family of pace and progress is advised, perhaps monthly, more frequently if there are clear changes. A gentle baseline should be established and only once that is easily coped with should gradual increases take place. Targets should not be exceeded on 'good' days. This will help to prevent relapses.
- All teachers, whether in school or at home, are advised to stick to agreed plans and make changes only after discussion with all involved, especially the child.

## Potential Problems

- Staff should know to look out for increasing paleness, decreasing concentration and/or slumped posture. This is the time to stop, even if it is less than the usual or arranged time.
- A child who asks to stop should be believed. They know how they are feeling.
- Temperature regulation can be affected. Some children may require extra warmth, whilst others may overheat very easily. An appropriate environment is important, as is permission to wear more/fewer clothes.

- Some children may need to eat at unusual times to control symptoms of varying blood sugar levels. There may be some food intolerances and these foods should be avoided.
- Sleep/wake patterns may be abnormal, so a child may fall asleep in class. This should not cause the child to be disciplined.
- The child may appear irritable or have mood swings. The causes are likely to be lack of sleep or hormonal upsets.
- Problems with language skills are common: the pupil may be unable to remember simple words and have difficulty with written words; speech may be slurred; word order may be reversed; speaking may be difficult and voice projection can be a big problem; singing may be impossible; the pupil may say different words from those intended; there may be inability to make sense of speech or lengthy phrases or sentences; speaking can be exhausting.
- Mathematical ability may be severely affected. Understanding of graphs, etc. may be difficult.
- Concentration can be greatly reduced and can vary. Trying to continue with work when concentration is fading is unhelpful and can be harmful. The term 'brain fog' describes this situation well.

- Symptoms of increased fatigue, exhaustion or muscle pain following study/attendance at school may not show themselves until a day or two later. Please believe the child and parents' reports of this because the symptoms may not always be obvious to the teacher at the time.

## Environment

- Environmental factors can cause or make symptoms worse, e.g. fumes from chemicals and flowers etc.
- Dark glasses or a peaked hat can help to reduce sensitivity to light. Fluorescent lighting should be avoided.
- A quiet area for break time and somewhere to sit can prevent symptoms worsening as noise levels and bustle increase. Volume of teaching videos, etc. should be kept to a minimum.

# Practical Help

- A rest area with a bed/couch may be needed, sometimes at short notice. Availability of more than one area may be useful if the child is in a class at some distance from the medical room.
- The child may require frequent access to the nearest toilet facilities and this should be easily permitted.
- The child may need to be reminded to avoid standing whenever possible.
- Extra support from a classroom assistant may be required.
- A scribe, tape recorder or laptop may need to be provided, especially where muscle weakness and/or pain are big problems.
- Careful assessment of the suitability, or otherwise, of PE lessons will be most important.
- Help to carry bags may be required.
- Walking between classes should be kept to a minimum and let the child use the lift. An open-ended permission card makes this easier.
- A wheelchair may be required between classes.
- Transport by taxi, etc. to school can save energy and allow the child to make best use of their learning time at school.

# Examinations

Staff and Examination Boards are advised to take into account: effort to reach exam centre; long spells of concentration required; exams at unsuitable times of the day; tight exam schedule which does not allow for recovery between exams. Therefore exams held at home at a suitable time, with rests, extra time and special consideration by the examiners may all need to be considered. Guidance Teachers can advise on liaison with the Exam Board.

*"Some young people will be too severely affected by their illness to participate in any form of education, even at home...a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed." (2)*

# Tips for Staff

Teachers/ Tutors are advised that the following can help the child-

- Speaking slowly and being patient – thought processes can be slow.
- Keeping explanations simple.
- Pausing and waiting for a response-it could take time.
- Not speaking while the pupil is thinking.
- Minimising processes to complete work, e.g. using worksheets and/or having an extra set of books for home to prevent the pupil from carrying heavy weights to and around school.
- Letting the pupil control the pace of the work.
- Stopping the minute the pupil needs a break.
- Asking the pupil about energy levels and 'brain fog', not how he/she feels.
- Letting the pupil use energy saving aids, e.g. laptops, but keeping the brightness down and avoiding flickering equipment.
- Listening carefully to the pupil and believing them.

# Sources of Advice on CFS/ME and Education

## Children In Scotland (Education Advice),

Tel; 0131 228 8484.

5, Shandwick Place, Edinburgh, EH2 4RG.

[www.childreninscotland.org.uk](http://www.childreninscotland.org.uk)

## Association of Young People with ME (AYME).

Tel; 08451 232389.

9a Vermont Place, Tongwell, Milton Keynes, MK15 8JA

[www.ayme.org.uk](http://www.ayme.org.uk)

## The Young ME Sufferer (TYMES Trust).

Tel; 0845 003 9002.

PO Box 4347, Stock, Ingatestone, Essex, CM4 9TE.

[www.tymestrust.org](http://www.tymestrust.org)

## Edinburgh ME Self Help (MESH).

Tel; 0845 625 2025

Membership Secretary; Paul Cooper.

[www.edmesh.org.uk](http://www.edmesh.org.uk)

## Action for ME.

Tel; 01749 670799.

PO Box 1302, Wells, Somerset, BA5 1YE

[www.afme.org.uk](http://www.afme.org.uk) and [www.a4me.org.uk](http://www.a4me.org.uk) (young people)

## Myalgic Encephalomyelitis Research Group for Education and Support. (MERGE)

Tel; 01738 451234.

The Gateway, North Methven St, Perth, PH1 5PP.

[www.mereseearch.org.uk](http://www.mereseearch.org.uk)

## ME Research UK

Tel; 01738 451234.

The Gateway, North Methven Street, Perth, PH1 5PP.

[www.mereseearch.org.uk](http://www.mereseearch.org.uk)





# Sources

- (1 & 2) 'A Report of the CFS/ME Working Group to the Chief Medical Officer', England, 2002.
- 'Report of the Short Life Working Group on CFS/ME to the Chief Medical Officer', Scotland, 2003.
- Children in Scotland.
- AYME.
- Tymes Trust.
- Stockport Outreach Teaching Service.
- 'Evidence Based Guideline for the Management of CFS/ME in Children & Young People', Royal College of Paediatrics and Child Health, 2004.
- Education (Additional Support for Learning) (Scotland ) Act, 2004.

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