

# Richmond & Kingston



## M.E. Group

Serving Richmond & Kingston Boroughs & the surrounding areas

### Useful Advice and Tips for Supporting Pupils with Mild or Moderate ME/CFS in Secondary Schools

#### Understanding ME

- ME/CFS can quite commonly follow glandular fever or some other infection or trauma, but can also come on slowly. It can sometimes occur in families and can occur in clusters, often after the summer.
- The main symptoms are physical and mental exhaustion, weakness, muscle pain, headaches, light and noise sensitivity and sleep disruption. Crucially for education, cognitive problems including slowed mental processes, problems constructing thoughts and finding words, poor memory and problems concentrating can be devastating. Students may develop special educational needs. (See our booklet for more explanation of how it feels to have ME).
- ME may be mild/moderate/severe or very severe and symptoms can vary considerably, therefore it is essential to adapt to the needs of each individual child and their current energy levels. Some pupils can manage time in school while others become confined to bed, unable to even feed themselves. Children with severe ME may be too ill to cope with school, home tutoring, or online study. (The case study in our presentation is an example)
- Symptoms often fluctuate from day to day and also within a day, depending on rest and activity being undertaken. What is possible one day, may not be so another. Like a poorly functioning battery, energy is finite and runs out quickly and the battery is hard to recharge.
- It is a hallmark of the illness that exertion beyond the child's energy supply causes symptoms to worsen and can lead to a downward spiral in which less and less can be attempted.

#### Principles that Support Recovery/Improvement

- Maximising the chances of a good prognosis depends on good management of the illness in the first year and thereafter.
- Ideally the child should try and find a level of activity they can sustain rather than following a destructive pattern of boom and bust which harms recovery and typically causes relapse.
- The child may have to choose between activities e.g. between washing and eating if they are severely ill. They may be exhausted after a shower or watching a 30 minute TV programme. Travelling to school and moving around school can use a lot of energy, leaving little for learning or healing.

- Adequate rest and good pacing are essential. Cognitive and physical activity can be equally exhausting and impact on all symptoms. Rest, means resting the brain as well as the body.

### **The early stages and during relapses**

- In early stages home tuition will often be required and this may be needed into the longer term. In some cases distance learning may be most appropriate.
- Pressure should not be placed on a sick child to attend school. Doing so is stressful and counter-productive and standard generated letters about attendance should be avoided.
- If the child is well enough, agree a reduced subject commitment and ensure staff send work home as agreed with the parents and child, or that can be made available online.
- Although this may be focussed on core subjects, ensure it includes things the pupil enjoys. If it has to be a choice, maybe drop the core and make the focus fun/therapeutic until the pupil is well enough to take on more.
- Be careful not to overload. Don't necessarily expect work to be done.
- Social isolation is a major issue. If the child feels able and would like to, enable occasional visits to school for social contact, if lessons are too much.

### **Supporting a child with ME back into school**

- Only when the child's health is sufficiently good/improved should re-integration be commenced and then only at a slow pace that's consistently manageable for the child.
- Everything needs to be planned around rests and conserving energy. If attending school, arrange shorter, flexible hours, reduced walking, sitting instead of standing, lifts/taxis to school etc. Regular rests and energy conservation are better than pushing through.
- Ensure frequent rest breaks are catered for, preferably in a quiet area where the child can lie down but adapt according to need, in discussion with the child and parents.
- Allow intermittent attendance for a lesson or two and late starts to the day, eg missing registration and assembly.
- Have systems in place to ensure the pupil is kept informed, especially of exam related deadlines and activities. E.g. deadlines for curricular trips or even final year photograph.
- Ensure supply staff know the child is sick and adapt what they do accordingly.

### **When the child who has ME is in class**

- Due to problems maintaining normal blood flow to the brain, it will likely help if the pupil is allowed to put their feet up in class and for rest periods to be lying down in a quiet space.

- A pupil may need to sit down or even lie down suddenly and is likely to find lengthy standing still difficult (eg. in a lunch queue, outside a classroom or at a work bench).
- S/he may fall asleep in class and should be tactfully left or supported (never ridiculed).
- Be alert to the child becoming tired cognitively and physically. A child may feel embarrassed to ask to take a rest. Teachers need to be alert to this and deal tactfully.
- The child should not be expected to both attend a lesson and do homework. S/he may well have to choose between the two and should not get into trouble for this having made it in, maybe against the odds.
- It is all too easy to assume that because a child is in school and has no visible symptoms, they must be well/recovered, especially as they may be trying to hide how they are feeling.

### **Mobility**

- It should not be assumed the pupil can walk more than a very short distance. This will vary from child to child (and some may need a powered wheelchair) and will depend on what else they have done or have to do that day. A few minutes walking around the school site may be completely exhausting and counter-productive for some. Even when partly recovered, it is a good idea to keep physical and mental activity similar and manageable from day to day

### **Physical education**

- The pupil should be exempt from PE. If they are approaching full recovery, they may be able to participate in part of a lesson but this needs to be very carefully managed as it is very easy to exacerbate symptoms and cause a relapse. Regular rest is better than pushing through.
- It is preferable for the child to go to the library or take a rest break than be expected to stand in the cold on the side of the pitch or do the activities normally assigned to those who have 'forgotten' their kit (this is poor, unproductive use of precious energy).

### **School trips**

- Alternative arrangements may need to be made for school trips, especially those associated with exam subjects, Special consideration may need to be given to mobility issues and travel arrangements, where using public transport may be unrealistic.

### **Examinations**

- It is usually helpful to limit the number of exams being taken at one time in consultation with the pupil and parents. The number that's practicable will vary from child to child.

- Children need to be kept on roll so they can be entered for exams.
- Some pupils benefit from doing a very limited number of exams each year. For example, a child accessing the school curriculum via distance learning from home might attempt two GCSE subjects a year in order to gain quite a respectable selection of GCSEs.
- If the pupil is doing exams - arrange an exam room with invigilation where s/he can lie down for regular rest breaks, allow food and drink (an energy drink may help if the pupil is not sensitive to caffeine), arrange for time extensions, a reader/amanuensis and/or to take the exams at home, if need be. This needs to be applied for well in advance.
- If needed, arrange for exams to be taken no more than one a day and only in the afternoon if that's when the pupil is functional.
- Accept that with sleep disturbance and reversal, pupils are not infrequently unable to function in the morning, though this will vary from pupil to pupil. Trying to force an early rise will just exacerbate symptoms and reduce chances of exam success.
- If they are to be attempted, practical exams may need to be spread over a week rather than a day or two. For example a ten hour art exam might be spread over five days, an hour before and after a lunchtime rest break.

### **Keeping in touch**

- Standard letters and formal meetings can be very stressful for the parents who are already grappling with the upheaval and distress of having a sick child. A focus on attendance can put unhelpful pressure on the family at a time they need support.
- Keeping in regular supportive telephone communication with the parents and also the child can be very welcome and constructive.
- Home visits may also be supportive, if well conducted and well received.

### **Medical considerations**

- If possible, rely on GP diagnosis rather than waiting for a consultant but also be aware that some GPs are still sceptical as they are not up to date with latest biomedical research and ME has not historically been included in medical training. NICE guidelines, though good in some respects, are woefully out of date.
- If necessary, exercise your duty of care regarding what is most appropriate for the child's education when it is clear they are not coping in school or relapsing at home after time spent in school.
- It is very important school attendance is not used as a form of graded exercise.