

## Strategies to support pupils with CFS/ME

- Reduce timetable / reduce number of subjects / flexibility around starting time
- Staff / peer awareness of the nature of the illness
- Part-time attendance: Targeting subjects and time of day
- Working in a separate area
- Supported tuition or one-to-one support on site in school
- Reducing movement around school and the amount the pupil has to carry
- Exemption from PE / games lessons (or part of the lesson)
- Taxi / subsidised transport to and from school to reduce travelling time and energy expenditure
- Limited homework timetable with extended deadlines for homework and coursework
- Extended time or rest breaks or other examination concessions
- Included social time in school plan
- Email links to school and friends

## Contact details

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# Chronic Fatigue Syndrome/ME Service for Children and Young People

## Guidance for Schools and Families



## **Chronic Fatigue Syndrome/ Myalgic Encephalopathy (CFS/ME) Service for Children and Young People**

There is an established service for children and young people with CFS/ME in this area. The service works with schools to support pupils with this difficult condition.

This service is provided by a multidisciplinary team consisting of:

- Physiotherapist
- Specialist Nurse
- Consultant Paediatricians
- Education Advisors
- Specialist Clinical Psychologist

The team provide assessment, therapy and treatment using the nationally recognised guidelines for children and young people with CFS/ME.

### **Impact on education**

CFS/ME may be a long and debilitating illness and may cause major disruption to a pupil's education.

Diagnosis may take some time, during which a pupil may have marked periods of absence and a fall in achievement. Once a diagnosis is made, a management plan is introduced and a baseline of activity identified. This may take several weeks. The impact on education will depend on the severity of illness. This could mean part-time attendance or support by ESTMA (Educational Support Team for Medical Absence) to fit attendance with additional needs.

Early intervention, such as putting in place a reduced timetable, may minimise the length of absence. It is important for pupils with CFS/ME to maintain their links with school even if, for some, these may seem minimal.

The symptoms of CFS/ME vary with the stage and severity of the illness and may fluctuate in intensity. CFS/ME can also be characterised by relapses.

### **Symptoms and their effects on the pupil's ability to access education may include:**

- Debilitating fatigue (physical and cognitive) exacerbated by exercise or activity with long recovery periods
- Fluctuations of intensity of fatigue - lack of energy for usual activity
- Severe headaches and dizziness
- Sleep disturbances
- Concentration difficulties and memory impairment
- Depressed mood, anxiety or weakness
- Muscle or joint pain - at rest and on exercise
- Nausea, changes in appetite, weight loss or gain, and abdominal pain
- Tender lymph nodes, sore throat and coughing
- Eye pain, increased sensitivity to light, vision or hearing disturbances
- Feeling too hot or too cold

When pupils are unable to participate in normal activities with their peers, this can lead to social isolation.

Any of the symptoms can have an impact on how a pupil engages in education, particularly:

- Cognitive problems, such as poor concentration or poor memory
- Fatigue in school (physical or cognitive)
- Emotional problems, for example, social isolation or low self esteem
- Poor school attendance
- Difficulties travelling to and from school

In 2015, the Government issued statutory guidance for pupils unable to attend school for medical reasons. As soon as pupils are diagnosed with CFS/ME, a support programme needs to be put in place as part of their management plans. Guidance to fit education will be carefully managed.

There are a number of strategies which can be used to support a pupil with CFS/ME but these may need to be modified or stopped, depending on what a pupil is able to manage. These arrangements need to be regularly monitored.

