

# Patient information

## **School Information**

Information for Schools and Educational Settings supporting children & young people with Chronic Fatigue Syndrome (CFS)

#### **Chronic Fatigue Syndrome (CFS)**

Chronic Fatigue Syndrome (CFS) is also known as Myalgic Encephalitis (ME). It is a relatively common condition in children affecting 1% of teenagers. CFS is one of the most common reasons for children not attending school.

This leaflet has been produced to help education settings understand and support students who have CFS and facilitate their engagement in home/schoolwork and attendance.

#### Symptoms of CFS

Children and young people with CFS report constant tiredness that is not relieved by sleep. They struggle to do things that they could easily participate in before, this includes physical, cognitive and emotional activity. They often report "brain fog" where they are not able to concentrate.

Other symptoms such as dizziness, pain, nausea and headaches are also associated with CFS. Children may also feel sad and lose their confidence and feel isolated from their peers.

### **Recovery from CFS**

Most children and young people will recover from CFS, but it is important to recognise that it is a fluctuating and unpredictable condition where symptoms can change in nature and severity over a day, week or longer. Overcoming CFS requires communication and support between the child, families, medical professionals and educational setting.

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Putting you first

#### Impact of CFS on schoolwork

Fatigue affects cognitive function such as concentration and memory, consequently children with CFS will usually fall behind on their schoolwork. New information can be difficult to understand and absorb, previously known work can be forgotten, and completing work can take longer.

#### **Supporting Children in Educational Settings**

Avoiding a 'boom bust' pattern of behaviour and regaining a healthy balance between sleep, activity, diet and rest is key. This is known as pacing. A child may need to reduce the level of activity they were doing therefore attending less school to regain a consistent attendance and then building it up from there.

Additional help may also be needed with their mental health and reintegrating into peer groups. Other recommendations to support the young person are:

- A named member of staff that the child, family and health professions can liaise with.
- Reduced timetable agreed by all with a graded approach as to how this will be adjusted according to progress made.
- Arrangements for arriving/leaving school if not within usual hours.
- Access to quiet areas for rest breaks without needing to ask or use a "take a break" card during lessons particularly for double lessons. Children with CFS can usually work for 35-45 minutes before needing to take a break.
- Flexibility in deadlines allowing more time for work to be completed.
- Exams to be completed in small groups and for public exams a request for reasonable adjustments should be made.
- Work to be available to complete online at home if the child is unable to attend school.
- Use of laptop and access to lift pass
- Balancing the timetable to include core & enjoyable subjects & sociable aspects of school.
- A support system for the child (buddy or peer)

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