

## SEVERE PAEDIATRIC CHRONIC FATIGUE SYNDROME OR MYALGIC ENCEPHALITIS (CFS/ME)

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### Abstract

Children with Chronic Fatigue Syndrome (CFS/ME) have severe fatigue that is disabling and has lasted longer than 3 months.<sup>1</sup> It is made worse by exercise or other activities and is associated with a variety of symptoms including: muscle aches and pains, headaches, and poor concentration.<sup>1</sup> Occasionally children are severely affected which means that they are unable to attend school and rarely leave the house. They often spend most of their time in bed, and can find light and noise are painful.<sup>1</sup> Usually they are unable to do most activities for themselves and may need a wheelchair. This is different to children with mild or moderate CFS/ME who will be able to do carry out most normal childhood activities and are attending at least some school.<sup>1</sup> Little is known about this group of children because it is rare and making a diagnosis requires a medical assessment. This means that studies that look for this in the population need to be both very large and have medical assessments.

In our study using the Avon Longitudinal Study in Parents and Children we found 5/5271 children who were unable to leave the house because of tiredness.<sup>2</sup> However, we do not know whether these children had CFS/ME or other conditions as they had not been assessed by a doctor. Using centralised school records to identify these children (which we have done previously for epidemiological studies<sup>3</sup>) is no longer possible as centralised attendance records are no longer held.

The literature that is available suggests that once children become housebound and stop going to school for more than 6 weeks, recovery and return to school is slow. Unpublished data from our cohort suggest that approximately 18% will recover eventually and a further 18% will attend some school. These figures are based on follow up that occurred between 8 and 35 months after assessment. This suggests that once children have been at home housebound for weeks, they are unlikely to fluctuate between attending school and being housebound within a short period of time. Because these children are unable to attend school, they need home tuition to fulfil their statutory right to education. We have chosen the BPSU as all children with medical symptoms who are unable to attend school will be seen by a paediatrician. This is because these children need a paediatric assessment prior to home tuition being provided by the local authority. Most of these children will not be seen by a child psychiatrist and therefore this study is not possible with CAPSS (Child and Adolescent Psychiatry Surveillance System).

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### Background

Children with chronic Fatigue Syndrome or myalgic encephalitis (CFS/ME) have persistent disabling fatigue for at least 3 months. The fatigue is made worse by activity and is not relieved by rest. Children with CFS/ME have other symptoms including muscle aches, headaches, and poor concentration.

Children with severe chronic fatigue syndrome or ME are only able to leave their house occasionally (if at all). They have severe fatigue and often severe pain and many require help with daily activities such as eating and washing. At the moment, we do not know how often children develop severe CFS/ME or what treatment they receive. This means the NHS cannot organise treatment for them.

In this study, we will ask every children's doctor in the UK whether they have seen a child that month with severe CFS/ME. We will then ask the doctor about their symptoms, how disabled they are and how long they have been unwell. We want to know what treatment children with severe CFS/ME get and we will ask doctors what treatment children were offered and what treatment they received. We also want to know whether children with severe CFS/ME get better and we will go back to doctors after a year to find out what happened to children in terms of treatment offered and whether they got better (or not).

### Coverage

United Kingdom and Republic of Ireland

### Duration

February 2019 to February 2020 (inclusive). Follow-up until February 2021 (1 year follow-up).

<b>Research Questions</b>	<p><b>Primary aim</b></p> <ul style="list-style-type: none"> <li>▪ To estimate the incidence of Severe Paediatric CFS/ME in children and adolescents under 16 years old (0 – 15.9 years) in the UK and Republic of Ireland over one year.</li> </ul> <p><b>Secondary aim</b></p> <ul style="list-style-type: none"> <li>▪ Describe the clinical features (including function) of children with severe CFS/ME</li> <li>▪ Describe the length of time from symptom onset to diagnosis</li> <li>▪ Describe the management of severe CFS/ME and associated resource use.</li> </ul>
<b>Case definition</b>	<p>Children aged 5 to 16 years who has been given a clinical diagnosis of CFS/ME with fatigue that is so severe that they are unable to attend school for more than one hour a week during the last 6 weeks of the school term.</p> <p><b>Notes:</b></p> <ul style="list-style-type: none"> <li>▪ If a child has had CFS/ME for a long period of time, they should be reported when the paediatrician becomes aware that they are not attending school.</li> <li>▪ School includes hospital school but not home tuition.</li> <li>▪ If a paediatrician is providing assessment during the school holidays or shortly after the school holidays, they should consider whether the child is able to attend school for more than one hour (or do a similar activity) during the last 6 weeks.</li> </ul>
<b>Reporting instructions</b>	<p>Report any child seen in the last month who meets the case definition in the UK or the Republic of Ireland.</p>
<b>Methods</b>	<p>Each paediatrician reporting a child who meets the above case definition of CFS/ME will be sent a clinical questionnaire by the study team.</p> <p>Throughout the study, all patient data will be dealt with in strict confidence, and affected children and their families will not be contacted directly by the FPIES study team at any stage</p>
<b>Ethics approval</b>	<p>This study has been approved by South West – Central Bristol REC (REC reference: 18/SW/0051) and has been granted Section 251 HRA-CAG permission (CAG Reference: 18/CAG/0051). Public Benefit and Privacy Panel for Health and Social Care (PBPP) approval in Scotland is awaited.</p>
<b>Support group</b>	<p>TBC</p>
<b>Funding</b>	<p>The study is funded by The National Institute for Health Research (Senior Research Fellowship, SRF-2013-06-013) and a grant from the Royal United Hospitals Bath NHS Foundation Trust.</p>
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