

Chronic fatigue syndrome in young people: the spectrum and the myths

Large telephone surveys in both the UK and USA suggest that chronic fatigue syndrome/myalgic encephalopathy (CFS/ME) in children is both surprisingly common (0.19–2%), and indiscriminate in who it affects (Jordan et al, 2000; Chalder et al, 2003; Jones et al, 2004). There is no gender preference, no social class gradient, and all ethnic groups are affected. The CFS/ME described in studies where patients are recruited from specialist care is much rarer and predominantly affects white females of higher socioeconomic status (Patel et al, 2003).

Why is there such a difference between those seen in specialist care and those described in the population? One explanation is successful health-seeking behaviour – families from a higher socioeconomic class have a better chance of finding treatment, especially when treatment is limited or rationed.

Although this may explain the difference in socioeconomic group, it doesn't explain the difference in gender ratio. Why are girls much more likely to be seen in a specialist clinic than boys? A population study from Wichita suggests that girls are more likely to present with recurrent sore throats and lymphadenopathy whereas boys are more likely to complain of concentration and memory problems (Jones et al, 2004). This may mean that girls are more likely to present to health services whereas boys are more likely to present to education welfare officers because of time missed from school.

These problems may be compounded by the fact that many clinicians either do not believe that CFS/ME is a real problem or do not know how to treat it (Thomas and Smith, 2005). Many feel unable to help and are uncertain about treatment approaches. There are several myths surrounding CFS/ME that may promote this behaviour.

Debunking the myths

Myth 1: CFS/ME is just yuppy 'flu

This myth was generated in the 1980s when the press latched onto descriptions

of this condition in those of higher social economic class. This was probably a result of successful health-seeking behaviour. As CFS/ME affects every social class and ethnic groups equally, the real issue is actually about those who are unable to access treatment and support.

Myth 2: CFS/ME is only seen in high achievers

The only longitudinal study looking at this question (Viner and Hotopf, 2004) showed that academic ability was not associated with the risk of lifetime self-reported CFS/ME. This is consistent with population studies which do not show a social class gradient although it is possible that high achievers and their families are more likely to present to specialist services.

Myth 3: CFS/ME is psychological

Between 25 and 70% of young people have an associated psychiatric disorder such as depression, somatization or anxiety (Carter et al, 1999; Garralda et al, 1999; van Middendorp et al, 2001; Chalder et al, 2003). Adolescents with CFS/ME have also been reported as having more psychological distress than young people with either juvenile rheumatoid arthritis or cystic fibrosis. However, none of these studies have been able to demonstrate the direction of causality. The high level of anxiety and low mood seen could be a result of suffering from a severe chronic disabling condition. The presence of anxiety

and low mood may also increase referral to a specialist centre thereby increasing the prevalence in these cohorts.

The only longitudinal study to investigate this (Viner and Hotopf, 2004) demonstrated convincingly that maternal psychopathology, parental illness, childhood or adolescent psychological distress, academic ability, atopy, birth order, birth weight and obesity are not associated with the risk of lifetime self-reported or physician-diagnosed CFS/ME. As with other conditions, it is possible that the presence of anxiety and low mood may worsen prognosis or make it harder to access rehabilitation. It is therefore important to identify these comorbid conditions but unhelpful to ascribe them as the cause of the condition.

Myth 4: Young people with CFS/ME never get better

Current evidence suggests that the prognosis for children (under 16 years) is good with at least 84% making a good or full recovery (Joyce et al, 1997). This is in contrast with the prognosis in adults which is much worse.

How does CFS/ME present in children and young people?

The Royal College of Paediatrics and Child Health (RCPCH) (2004) defines CFS/ME in young people as disabling fatigue without another cause (Table 1). In the RCPCH definition there is no minimum time requirement for the fatigue and

Table 1. Royal College of Paediatrics and Child Health (RCPCH) definition for chronic fatigue syndrome/myalgic encephalitis (CFS/ME)

RCPCH definition for CFS/ME	Generalized fatigue persisting after routine tests and investigations have failed to identify an obvious underlying 'cause'. In CFS/ME the fatigue is likely to be associated with other classical symptoms and is classically exacerbated by effort (both mental and physical)
Other classical symptoms	Severe malaise, headaches, sleep disturbances, concentration difficulties, memory impairment, depressed mood, myalgia/muscle pain at rest and on exercise, nausea, sore throat, tender lymph nodes, abdominal pain and arthralgia/joint pain
Symptoms reported less often	Feeling too hot or cold, dizziness, cough, eye pain/increased sensitivity to light (photophobia), vision or hearing disturbances (hyperacusis), weight loss or gain, muscle weakness, lack of energy for usual activities and diarrhoea

From RCPCH (2004)

no required symptoms, although common and less common symptoms are described. This is in contrast with the Centers for Disease Control and Prevention (CDC) definition for adults which requires 6 months of fatigue and at least four other symptoms (Fukuda et al, 1994).

The fatigue in CFS/ME must be disabling, i.e. severe enough to result in a reduction of activities. The fatigue and other symptoms are made worse (payback) by exertion whether the exertion is physical, emotional or cognitive. The payback is often delayed to the following day or later, and can last a day or longer. When children are moderately to severely affected, they can get payback after what appears to be a very small increase in activity. This may present as children doing alternate days at school or having increased symptoms after, for example, home tuition. It is important to recognize this when planning rehabilitation programmes otherwise the rehabilitation itself can make the illness worse.

In addition to the fatigue, an almost universal complaint is sleep disturbance. Usually children and adults find it hard to get off to sleep or describe a restless or broken sleep. They usually find it very difficult to get up in the morning and do not feel refreshed after they sleep. Unrefreshing sleep is part of the CDC criteria for CFS/ME in adults and is a useful clinical sign.

There are many other symptoms described in CFS/ME both in definitions and in population studies. It is important to recognize that not all children will talk about fatigue at presentation. Children may present with concentration and memory problems which is consistent with population studies which have shown this is a significant problem. The memory problems appear to be short- and medium-term problems which are very disruptive for children attending school. Young people talk about having a lesson one day and forgetting the content the next day. This is in addition to the concentration problems as they phase in and out of conversations, making learning even more difficult.

Recurrent sore throats and lymphadenopathy, headaches, muscle and joint pain are part of the adult CDC definition for CFS/ME and these symptoms are commonly seen in children. Children may get labelled as having recurrent 'tonsillitis' every 2–3 weeks because they keep pre-

senting with sore throat, tender lymph nodes, muscle and joint pain. The diagnosis of CFS/ME must be considered for a child who presents in this way if there is associated disabling fatigue.

The severity and therefore presentation of this condition is very variable. Some children are only mildly affected and able to attend full-time school but do nothing when they go home, or miss school regularly at the end of the week. At the other end of the spectrum, some children and young people are so severely affected that they are unable to get out of bed. Their symptoms are similar to those described above but much more severe. They are likely to have noise and light sensitivity and may be sensitive to smells (such as perfumes), medication and some food types. Very little is known about this group of patients and almost nothing is published, but clinical experience is that most do well with the right support, help and rehabilitation programme.

If one sees a child or young person with CFS/ME it is important to exclude other medical or psychological causes for the fatigue. Screening investigations are important and history and examination may point to other investigations which are necessary. Blood screening investigations should include full blood count, erythrocyte sedimentation rate or viscosity; C-reactive protein; urea, electrolytes and creatinine; liver function tests, random glucose, thyroid function, CPK, ferritin and coeliac screen. The urine should be dipped for protein, blood and glucose.

Conclusions

CFS/ME is common and affects children and young people from every background. Clinicians are poor at both recognizing the condition and treating it. With correct management and support, however, the outlook for children and young people with this condition is much better than many clinicians realize. [BJHM](#)

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Further reading

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KEY POINTS

- Chronic fatigue syndrome/myalgic encephalitis (CFS/ME) is surprisingly common in children.
- CFS/ME may present as recurrent tonsillitis or with memory and concentration problems.
- The prognosis in children is good and it is therefore important to offer effective rehabilitation.