

ME/CFS/PVFS

An Exploration of the Key Clinical Issues

CHAPTER TEN

Children and adolescents

*Prepared for health professionals and
members of The ME Association by:*

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10.1 Epidemiology

ME/CFS has been reported in children as young as five, and there appears to be a peak onset of symptoms around 13 to 15 years of age. But there is currently very little reliable information on the prevalence of ME/CFS among children and adolescents. The Chief Medical Officer's Working Group report (CFS/ME Working Group 2002) referred to a prevalence rate of 0.07% for children and young people. One study (Dowsett and Colby 1997) indicated that it is the commonest reason for long-term sickness absence from school. A more recent report has highlighted the fact that unidentified ME/CFS is a major cause of absence from school (Crawley *et al* 2011).

10.2 Diagnostic assessment

Diagnostic assessment of possible ME/CFS in this age group is very similar to that in adults. However, children tend to present rather differently to adults, and symptoms such as headaches, abdominal pain and disrupted sleep patterns tend to be more prominent. Collin *et al* (2015) investigated differences between young children, adolescents and adults with ME/CFS. They found that younger children had a more equal gender balance compared to adolescents and adults. Younger children were less likely to have cognitive symptoms and more likely to present with a sore throat. Adolescents were more likely to have headaches and less likely to have tender lymph nodes, palpitations, dizziness, general malaise and pain compared to adults. Adolescents were more likely to have co-morbid depression and less likely to have anxiety than adults. The authors of the study concluded that paediatricians need to recognise that children with ME/CFS present differently to adults, and they queried whether these differences may reflect a different underlying pathoaetiology in children and adolescents.

Symptoms relating to hypermobility syndromes and autonomic nervous system dysfunction, including postural orthostatic tachycardia syndrome, can also be present in children and adolescents (Wyller and Helland 2013). As with adults, children with ME/CFS may have significant problems relating to cognitive dysfunction, especially in relation to sustained attention, switching attention, auditory learning and immediate recall (Tucker *et al* 2011). The degree of cognitive dysfunction will obviously need to be taken into consideration when dealing with school attendance and educational issues.

A retrospective case note review of 131 children and adolescents attending a hospital-based specialist service found that 56% had at least one co-morbid condition – the most common being psychiatric, gastrointestinal, respiratory and musculoskeletal conditions (Oliver and Patel 2012).

There are other diagnoses (see Table 7) that in some instances need to be excluded by further investigation. So questions need to be asked, where appropriate, about the use of recreational drugs and alcohol. The tragic case of an Australian girl, who had been diagnosed as having ME/CFS but did in fact have mitochondrial neurogastrointestinal encephalomyopathy (MNGIE), illustrates the importance of a thorough specialist assessment for all children and adolescents who fall into the more severe category.

Rowe *et al* (2018) have recently reported on three children with severe ME/CFS where the symptoms improved after recognition and surgical management of cervical spinal stenosis. They concluded that prompt post-surgical restoration of more normal function suggests that cervical spine stenosis contributed to the pathogenesis of refractory ME/CFS and orthostatic symptoms. The improvements following surgery emphasise the importance of a careful search for myelopathic examination findings in those with ME/CFS, especially when individuals with severe impairment are not responding to treatment.

10.3 Management

Management of children and adolescents is similar to that of adults but with less emphasis on the use of drug treatments.

The MEA website has a list of specialist referral services for children and adolescents, but these are very few in number. Consequently, some children and adolescents still face unacceptable delays in obtaining a diagnosis and/or have great difficulty in finding appropriate advice on management (Webb *et al* 2011).

Appropriate liaison with local education authorities, schools and teachers, which is aimed at keeping education going through the use of home tutors, internet-based distance learning and part-time attendance, is vital. Children who are sufficiently unwell to be away from school should generally be under the active care of a paediatrician. Reduced school attendance in children with ME/CFS is associated with reduced physical function rather than with anxiety (Crawley and Sterne 2009).

It should also be noted that children and adolescents with ME/CFS may be eligible for various state sickness and disability benefits.

10.4 Prognosis

It is generally agreed that the prognosis for children and adolescents is much better than for adults (Katz and Jason 2013). A 13-year follow-up study of 46 children and adolescents reported that 80% had a satisfactory outcome, although the majority had mild to moderate persisting symptoms (Bell *et al* 2001). 20% of this group remained ill with significant symptoms and activity limitation.

10.5 Information and support

There are registered charities that deal specifically with children and adolescents with ME/CFS – The ME Association works very closely with The Young ME Sufferers Trust, also known as Tymes Trust. Tymes Trust has been recommended as providing the

most comprehensive information regarding the education of young people with ME (Carruthers and van de Sande 2012). Tymes Trust can be particularly helpful where advice on educational or child protection issues is required. Tymes Trust website: www.tymestrust.org

In December 2004, the Royal College of Paediatrics and Child Health published an evidence-based guideline on ME/CFS in children and adolescents (Royal College of Paediatrics and Child Health 2004). Although the guideline contains much useful information, The MEA was unable to endorse the section on behavioural interventions because it believes that these have not been covered in a balanced manner. The guideline is available here: <https://tinyurl.com/hrrewew>

The MEA has an information leaflet covering children and adolescents with ME/CFS and a To Whom It May Concern letter covering exams and the modifications that may be appropriate/justified for those with ME/CFS. We also have a new leaflet covering all aspects of university and college life in relation to ME/CFS and a 'To Whom It May Concern' letter that can be used in relation to modifications to course work and exams.

2018 Update

Cow's milk allergy

Rowe *et al* (2016) examined the prevalence, clinical features and influence on illness severity of cow's milk protein intolerance in young people with ME/CFS. They defined intolerance to milk protein if subjects reported (i) no evidence of immediate or anaphylactic reactions to milk, (ii) at least 2 of the following 3 chronic symptoms: gastroesophageal reflux, early satiety and epigastric/abdominal pain, (iii) improvement in upper gastrointestinal symptoms on a milk protein elimination diet and (iv) at least 2 recurrences of upper gastrointestinal symptoms >two hours following open re-exposure to milk protein. Seventeen met study criteria for cow's milk protein intolerance. Compared to milk-tolerant subjects, milk-sensitive participants had significantly worse health-related quality of life at baseline but not at six months (after institution of the milk-free diet). They concluded that cow's milk protein intolerance is a common problem in young people with ME/CFS and is a treatable contributor to their symptoms.

Paediatric primer

An international group of health professionals, including MEA paediatric adviser Dr Nigel Speight, have produced a comprehensive paediatric primer that covers all key aspects of clinical assessment, diagnosis and management of ME/CFS in children and adolescents (Rowe *et al* 2017). The primer is available to download from the documents archive on the MEA website.

SMILE trial

The SMILE trial was an attempt to determine the efficacy of the Lightning Process when delivered in addition to specialist medical care in the treatment of ME/CFS for children and adolescents. The MEA has a number of concerns about the way in which the Lightning Process has been promoted to people with ME/CFS. Following publication of the results of the SMILE trial (Crawley *et al* 2017) we also expressed a number of concerns relating to the way the SMILE trial was conducted and reported. The MEA has produced a detailed research review of the SMILE trial. This can be found in the October 2017 news archive on the MEA website: <http://www.meassociation.org.uk?p=33970>

Education and Child care proceedings

The 2002 Chief Medical Officer's Report on ME/CFS has an excellent chapter covering Children and Adolescents with ME/CFS. The report can be downloaded from the document archive section of the MEA website. As disputes relating to education and child protection are still quite common, the CMO guidance is also included here:

5.2.6 Education

Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. A critical element of the child's management is assessment and provision of educational needs. An educational plan is not an optional extra but an integral part of therapy, just as play is for the younger child. A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.

The co-ordinating clinician is then responsible for early referral to the Education Welfare Service to ensure that education is minimally disrupted. Adequate provision of continuing education needs close liaison between GP, community paediatric services, education services, the young person, and their family.

Some young people will be too severely affected by their illness to participate in any form of education, even at home. A resumption of education, in whatever form, should be managed in keeping with the general principles of activity management as outlined in Chapter 4 and Annex 6. Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.

With support and reassurance, both schools and families can reach a position where the child is attending their school for short periods, is working in a separate area quietly if need be, can rest or work as their ability to concentrate fluctuates through the day, and can maintain some contact with their peers. Gradually they can be reintegrated into the mainstream education system. The advantage of this approach is that it minimises the isolation of the child once he or she is able to get out of the house. It does require sensitive negotiation with the school and a tolerance on all sides.

Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

5.2.8 Child protection

On occasions, families of child sufferers with more severe CFS/ME have been the subject of child protection concerns. The Working Group notes that neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education for such a patient by the parents/carers and/or young person constitutes evidence of abuse.

Nonetheless, children with CFS/ME may suffer harm, and this is part of the differential diagnosis. It is important to listen to the child, as well as to family members and parents/carers, to respect their experiences, and to give due weight to their views, especially the child's. The young person should be given the opportunity to speak with the clinician, with or without their parents/carers.

In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection procedures or initiating care proceedings in a family court – Social Services should be made aware that medical opinion in this area is divided, and consideration should be given to obtaining a further opinion from an expert medical practitioner with a specialist knowledge of CFS/ME. Working together to safeguard children, issued jointly by the Department of Health, the Department for Education and Skills, and the Home Office, sets out the interagency arrangement to protect and safeguard children's welfare. This should be followed when there are concerns that a child may be or is likely to suffer significant harm.

Children and adolescents – key points

- ME/CFS affects children and adolescents - where it is one of the commonest causes of long-term sickness absence from school.
- There are similarities and differences in how ME/CFS presents in children and adolescents when compared to adults. Children are more prone to abdominal pain, nausea, and variations in appetite, which can lead to weight gain or weight loss.
- ME/CFS is likely to have a significant impact on all aspects of normal life along with the child's physical, emotional and intellectual development.
- The illness will also have a significant impact on all other members of the family.
- Care should be delivered according to a flexible patient-focussed treatment plan that is designed in collaboration with the child and parents, and is regularly reviewed.
- Children who are sufficiently unwell to be permanently off school should be under the care of a paediatrician.
- Educational management should normally include a letter to the school which explains how key symptoms are going to impact on every aspect of school life and what sort of modifications will need to be made to help those children who are still able to remain at school, or are intending to return to school on a flexible or part time basis.
- Ensuring that everything that can be done to continue with education – either at home or at school – is an essential part of management. An education plan should form an integral part of management.
- Arrangements for transition from paediatric secondary care to adult medical services should be put in place well before it occurs.
- The prognosis for children and adolescents is far better than for adults with a significant proportion returning to normal health.
- Exercising parental choice over treatment and education provision should not be regarded as evidence of child abuse. Where there is any doubt a further opinion from a doctor with specialist knowledge of ME/CFS should be sought.