

**Oxfordshire ME Group for Action (OMEGA)  
Experiences of Children with ME  
July 2018**

**Executive Summary**



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#### **Inequity in Meeting Children's Health and Education Needs.**

##### **Introduction:**

The seriously disabling condition ME affects many school-aged children and young people. Recent research shows 1% of enrolled secondary aged children miss at least 20% of school because of ME/CFS<sup>1</sup>. Many people ill in childhood do not recover. They are in permanent relapse – often severely ill – after being asked to do more than they are able in the early stages. Some are unable to eat, speak or move; some die of the illness or its complications.

OMEGA<sup>2</sup> – the local patient support and campaign group in Oxfordshire – and national charities supporting children with ME, often hear accounts of unhelpful and ill-informed responses from GPs and from school and social services staff. Children are vulnerable to adult judgement and decisions.

This survey systematically reports the experiences of children and their families and makes recommendations. *In this summary verbatim responses are in italic.* The full report with references and annexes is available at [www.omegaoxon.org](http://www.omegaoxon.org).

The entire family is affected. A child who is clearly unwell, with no diagnosis or good advice, *add to this unhelpful responses from the school, insisting on attendance* and this is a recipe for disaster for a child with ME and their entire family. Lack of diagnosis and inappropriate provision cause additional enormous stress and worry for the child and their parents and do not help his/her health.

Families' experiences vary; some schools and clinicians are helpful, many are not. It is important to learn from any example of poor practice in order that it is not repeated. The lived experiences reported by our respondents echoes findings from other regional and national reports into the experiences of young people with ME/CFS. The evidence of adults who had ME as children, many of whom are still severely affected, is telling.

One of the most shocking findings was that children and their parents are still often not believed by doctors and school staff.

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1 ME/CFS is what NICE (National Institute for Health and Care Excellence) calls the illness in 2018; this name now replaces the outdated CFS/ME used by the NHS since 2002 on the recommendation of the then Chief Medical Officer.

2 OMEGA (Oxfordshire ME Group for Action) [www.omegaoxon.org](http://www.omegaoxon.org) is the local support and campaigning group for people with ME/CFS in Oxfordshire. Following the Chief Medical Officer's Report 2002 it successfully campaigned for the commissioning of a community service (now called the Oxfordshire CFS/ME Service) which helps adults and young people of 14 years and over.

## **ME in children:**

The WHO lists ME as a serious neurological illness. Common symptoms are painful, disabling exhaustion and malaise very different from healthy fatigue, muscle pain, cognitive problems (poor concentration and short-term memory) all made worse by any activity. In children and young people, the brain and nervous system are developing. The effects of a neurological illness are therefore particularly dramatic for young people, and cause cognitive difficulties; problems with thinking, concentrating and remembering. Therefore, school work is affected; studying at all may be impossible, and the length of time children can do any school work, even at home, is curtailed. Many children cannot understand or retain written information and may not be able to use screens (iPad, smartphone, laptop) or watch videos or TV.

Being ill affects the rest of their lives too, as one parent put it: *The plethora of issues that are connected with their young age and the complex and subtle effect that most illnesses have on this group of people.*

There is no treatment but help can be given in diagnosis, medication for some symptoms, support to manage the condition, family support, liaison with schools and other agencies to access practical and financial assistance. Many parents have to give up work to look after very ill children. Advice for careful avoidance of overexertion can help avoid deterioration and facilitate improvement.

There is often a long-term effect. Melvin Ramsay commented even in 1988 on ME showing 'an alarming tendency to become chronic'. The report shows several cases of the illness in children continuing into adult life with drastic effect. One adult respondent to this survey is still *housebound most of the time, trip out in a wheelchair roughly every 10 days.*

## **Numbers:**

Based on the predicted school-aged population in Oxfordshire, there are likely to be 412 cases among secondary-aged students in 2018/19. (For primary-aged students in 2016/17 there may be more than 500 cases.) Clinical experience shows fewer cases among younger children, but even with a margin of error, this is a serious medical problem. Twenty-five percent of affected children are likely to be severely affected.

## **History:**

The issue of ME/CFS in young people is not new. Numerous medical reports, diagnostic criteria and treatment guidelines have been published. For schools there is relevant legislation for Appropriate Education, and also Statutory Guidelines from DfE (2013, 2017). These legal obligations are not being observed in many schools.

### **Aims and Method of the survey:**

This was a small qualitative survey using open questions. As well as from OMEGA members, the online survey elicited responses from all over the country. The aim was to report on the lived experience of families with the illness.

We asked what was unhelpful, and what was helpful about managing ME in the family; we asked what people would like from a community service like the Oxfordshire CFS/ME Service. We asked what education services could do to help students with ME.

### **Who replied:**

Twenty-eight people responded, about half from Oxfordshire (at least 12/28 – some didn't give their county); most (18/28) were from a parent or family member and 6/28 from adults who were ill as children.

### **What was helpful:**

- Some specialist teams including the community Oxfordshire CFS/ME Service (accessible only to people over 14), some GPs
- patient groups and
- information about the illness.

Cited were: *Doctors who listen and try and understand and who are able to say, 'I don't know.'* One specialist team: *covers absolutely every aspect of coping with ME physically, mentally, emotionally and intellectually.*

### **What was unhelpful:**

- Some medical services, some GPs (poor knowledge/training) and hospital services.
- The assumption that depression is causal when it is a consequence of illness.
- Lack of or delays in diagnosis and referral and the consequent effects on education, summed up by one parent: *Early diagnosis would make it easier for a school to deal with because until they have a diagnosis then it is very difficult for the school to make arrangements.'*
- Not listening to children and parents and pressure on families, bordering on bullying. One respondent said: *People encouraging me to 'do more' and not listening, as if I could somehow magically rehabilitate myself better.* They also said they: *... often felt very pressurised and sometimes threatened, when people tried to push me to get better, not realising that it wasn't within my power, or theirs.*

Good practice is possible: *The GPs were not helpful at all in our practice. Very patronising and condescending. Made you feel like that you were making it all up. [Then] a new doctor arrived and was fantastic. She couldn't help enough.*

### **What did people want from a clinic service like the Oxfordshire CFS/ME Service?**

- Again, and identified throughout the responses: Listen to and believe young person and their parents, offer practical advice.
- Early and correct diagnosis. A clear referral pathway. One young person summed this up: *I waited 6 months for an appointment, before being told I was not eligible because I was not diagnosed by a paediatrician. Instead I had to be referred to PCAMS<sup>3</sup> (sic), a waste of everybody's (sic) time.*
- Medication for sleep and/or pain.
- Liaison with schools is crucial; people needed a service to liaise with and provide information to the school, help with special arrangements for exams, online education and home tutors, and explain the difficulties young people have with cognitive function.
- Wider support for family. Liaison/contact with other services and agencies e.g. Benefits Agency, schools, Social Services for funding for a PA. A parent asked for help to *liaise with benefits agency for parents who have to give up work to become full-time carers.*
- No minimum age of access to a clinic service. *This Oxfordshire community service is only available to people of 14 years and over.* This comment also points to difficulties as there is no clear transition to adult services. (There are relevant 2016 NICE Guidelines.)

### **What can schools do to help students who have ME? Have you any comments about other education services?**

Other comments about education provision were made throughout the responses. They are summarised here:

- Listen to, believe and take seriously the child and family. Work with parents – do not blame them for the child's illness. (This latter comment was a repeated theme in many responses.) *Stop blaming parents and Stop ridiculing or belittling the children who are ill with ME.* Be aware of the deleterious and long-term consequences of pushing the child beyond what they are able to do sustainably and without ill-effects.
- Train staff and school nurses about ME and particularly how cognitive issues affect studying and remembering.
- Prevent or deal with bullying. Foster continued contact with peers in school.
- Be *flexible* in requiring attendance. Focus on supporting the ill child rather than attendance records. Understand that school attendance is not the best measure of health, or indeed of learning. *Schools, [ ] don't*

*have enough knowledge and are concerned with their attendance figures rather than supporting an ill child.*

- Any alternative educational provision in Oxfordshire (home tutor, hub, NISAI Virtual Academy etc.) should be provided *flexibly* in respect of timing and length of session. *Strong support for education of children based on their needs – at home if necessary rather than using school attendance as the sole measure of improvement.*

It is essential that the needs of the child and the nature of the illness be understood, particularly its cognitive effects, which make concentrating and remembering difficult. (As indicated above.)

- *I was given 5 hours home tuition per week in 2 x 2½ hour sessions. This was far too much and contributed to the major deterioration I was experiencing. [...] this was the minimum that was allowed. [...] When a specialist recommended 3 x ½ hour sessions instead this was implemented and it contributed immensely to my quality of life for a number of years. The difference between these short lessons and the long unsuitable ones was huge – suddenly life became much more liveable and happier.'*
- *On-line school was great, but the 'independent learning' (homework) was too much at the time we used it. The school felt that this was our child not bothering so pressured us to stop on-line learning and return to attending school. The on-line school had no work to mark so couldn't report much more than how well s/he interacted during the lesson.*

### **Recommendations:**

- Training for GPs in diagnosis and appropriate advice for young people and for educators about the illness and its effects.
- The extension of the Oxfordshire CFS/ME Service to young people under 14 years of age.
- Monitoring of adherence to the appropriate Statutory Guidelines in schools. Extension of existing good practice in some schools in the provision of appropriate education to all educational establishments.
- Training for school staff. Policy development in schools.
- More training for School Nurses.

### **Conclusion**

This qualitative survey systematically describes evidence from a small sample. There is huge stress to whole families (particularly siblings) from having an undiagnosed very sick child, with additional pressure from the school about attendance. Such stress is preventable. Poor practice should not be repeated. Many adults in this survey, who had ME as children, are still severely affected.

Patricia Wells, Priscilla Kew and OMEGA members  
For OMEGA, July 2018

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**Summary of Conclusions/Findings:**

The findings are mixed, but the consequences of poor practice, for children who are often vulnerable to adult judgments, are profound. Children and their parents are angry about the way they are treated. When handled poorly, schools are making ill children more ill and may be helping to cause a lifetime of illness and disability. Believe them and their families when they say they are ill. Early recognition of the illness is crucial.

- Some adult respondents had ME as children and many are still ill, some severely disabled by the illness. Clinical experience indicates that ME in children, when treated inappropriately, often persists into adulthood.
- Children can become more ill or have a relapse after being made to do more than they are able. This is consistent with a clinical view that early diagnosis and sufficient rest in the early stage may prevent later severity. Inappropriate medical services and interventions can make the illness worse
- The experiences of our respondents were varied. Good helpful strategies make recovery more likely and prevent unnecessary stress on families.
- Correct diagnosis is the gateway to schools' provision of appropriate education.
- Inappropriate provision and lack of diagnosis causes additional stress and worry for children, their parents and the whole family. Having a child who is clearly unwell, a lack of timely diagnosis and advice, and school insistence on attendance do not help the child's health.
- There is good published evidence for what is helpful to children with ME.
- The Oxfordshire CFS/ME Service (a community service) has helped some young people and should be available to children under 14 years old.
- Training is needed for GPs and schools about the diagnosis and treatment of this illness
- Statutory Guidelines (2013) and (2017) specify what schools are obliged to provide. This is clearly not being adhered to in many schools.
- There is good practice in some schools indicated by the few positive statements. It is possible for schools to respond helpfully and constructively to the sick child and their parents about education. All other schools should learn from this. There should be a consistent policy for provision and its implementation for sick children throughout the county.

Note on Treatment for ME: There is no known cure for ME/CFS. Previous claims for the efficacy of CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) as treatments for the illness are now discredited (*Journal of Health Psychology*, Vol. 22, No. 9, 2017). The NICE Guidelines (2007) are now under active review and revision. As in other illnesses like cancer, some patients *may* find pacing, time management or CBT helpful in managing the illness. OMEGA supports urgently needed biomedical research in Oxford and worldwide.

Doctors can provide timely diagnosis, medication for pain, insomnia etc., liaison with schools, sympathy and support for the family, referral for practical and financial help and above all listening to and believing the young person and their family.