

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

**Full report**



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Children with ME/CFS and their families are suffering needlessly. This serious condition is invisible and not well understood by medical and educational services. These services do not appreciate the seriousness of this illness and children's needs are not being met. This report describes the results of a brief qualitative survey of families in Oxfordshire carried out by OMEGA<sup>1</sup> – the local patient support and campaign group – and makes proposals. All the documents listed in Annexes are available in the shared Dropbox folder [www.dropbox.com/sh/jdp172a1wrlywqj/AAAr2HvgiUJ6mEPET0PD\\_mFva?dl=0](http://www.dropbox.com/sh/jdp172a1wrlywqj/AAAr2HvgiUJ6mEPET0PD_mFva?dl=0)

## 1. Introduction

Research indicates that CFS/ME<sup>2</sup> is 'the biggest cause of long-term sickness absence from school in both pupils and staff' (Dowsett and Colby, 1997). More recent epidemiology research (Crawley, Emond, Sterne, 2011) shows 1% of enrolled secondary-aged children missed at least 20% of school because of CFS/ME.

## 2. The Illness

ME is recognised by the WHO as a serious neurological illness. The most common symptoms are painful, disabling exhaustion and malaise quite unlike healthy fatigue, muscle pain, cognitive problems (poor concentration and short-term memory), weakness, severe headaches, sleep disturbance and digestive symptoms. There is often acute sensitivity to light and sound. All are exacerbated by any activity – mental or physical. There is a marked effect on quality of life. The symptom pattern varies between patients and over time. People living with this condition are of *all ages* and from all ethnic and economic groups. (For internationally agreed diagnostic criteria see Annexe 1.)

## 3. Numbers in Oxfordshire

Annexe 2 shows the current and predicted school-aged population in Oxfordshire. Research (Crawley, Emond, Sterne, 2011, *ibid*) shows a prevalence of 1%, so for secondary-aged students in 2018/19 there are likely to be 412 cases in the county. For primary-aged students in 2016/17 there may be 542 cases. (There is no reliable epidemiology for this age group, but this figure assumes a similar prevalence to that in older children.) Clinical experience shows fewer cases among younger children, but even with a

<sup>1</sup> 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 of 2002, it successfully campaigned for the commissioning of a community service (now called the Oxfordshire CFS/ME Service) which treats adults and young people of 14 years and over.

<sup>2</sup> In 2018 NICE (National Institute for Health and Care Excellence) calls the illness ME/CFS; this name now replaces the outdated CFS/ME used by the NHS since 2002 on the recommendation of the then Chief Medical Officer.

margin of error, this is a serious medical problem. Twenty-five percent of affected children are likely to be severely affected (25% Group, n.d.).

#### **4. The Illness in children**

In children and young people, the effect of a neurological illness on the developing nervous system is dramatic. There are profound effects on the developing brain. Cognitive symptoms resulting from the illness cause problems with thinking, concentrating and remembering. This will cause significant limitations in the length of time children can do any school work, even at home. If they are very ill, studying at all may be impossible. Children can become very ill indeed with ME: 57% become bed-bound at some point. Moreover, 68% are too ill to attend school. The illness and its effects are becoming more widely understood in adults, but this is not yet the case for children. OMEGA and the national charities<sup>3</sup> supporting children with ME frequently hear accounts of unhelpful responses from GPs and from school and social services staff. These are also reported in the press (Gillespie, 2014) (Haywood, 2012). (Also see Sections 5 and 7 below).

There may be a long-term effect. Melvin Ramsey commented as long ago as 1988 on CFS/ME showing 'an alarming tendency to become chronic' (Ramsay, 1988). This report describes several cases of the illness in children continuing into adult life.

#### **5. History**

This is not a new issue. Numerous reports and diagnostic criteria are detailed in the list of sources. The Medical Royal Colleges recognised the illness and made recommendations in 1996 (The Medical Royal Colleges, 1996). The Chief Medical Officer's Report made recommendations for children in 2002 (Hutchinson, et al., 2002, pp. 58–66). An earlier National Service Framework for Children and Young People with CFS/ME was updated in 2004 (DoH/DfES, 2004). The Royal College of Paediatrics and Child Health published a Guideline in 2004 (Beverley, Campion, Clinch, 2004). An internationally agreed Primer for Diagnosis and Management in young people was published in 2017 (Rowe, et al., 2017) (see Annexe 3).

OMEGA published a campaigning issue of its Newsletter in 2009, giving case studies of children and families (Annexe 4). In 2012 it published (with the then LINK [Local Involvement Network], the precursor to Healthwatch) a Survey of Oxon GPs showing that they were 'significantly less satisfied with services for younger patients and the majority (68%) would be in favour of a multidisciplinary team for children with CFS/ME' (OMEGA/Oxfordshire LINK, 2012). Press publicity about young people in Oxfordshire includes national

<sup>3</sup> Tymes Trust (The Young ME Sufferers' Trust), [www.tymestrust.org](http://www.tymestrust.org) and AYME (Association of Young People with ME); AYME has now merged with Action for ME: [www.actionforme.org.uk/children-and-young-people/introduction](http://www.actionforme.org.uk/children-and-young-people/introduction).

reports about Oxfordshire residents Sophie Ellis (Haywood, 2012) in *The Sun* and more recently Zoë Fabian in the *Oxford Mail* (Robinson, 2014).

It is scandalous that despite all the evidence of the seriousness of this illness, and reports and recommendations for appropriate services for them, this report will show that children are *still* not getting the provision they need. This causes great stress and worry in families. Moreover, there are legal requirements for the provision of education for children who are ill.

## **6. Legislation: 'Appropriate Education' and Statutory Guidelines (2013 and 2017)**

In 2002 the then Department for Education and Skills published 'Statutory Guidelines for the education of children with medical needs' (no longer available). This provided guidelines for 'children and young people to access education appropriate to their medical condition'.

More recent Statutory Guidelines have been published, one for the education of children too ill to be in school (DfE, 2013) and another for the education of ill children who are able to attend school (DfE, 2017). These specify that effective and suitable education should be provided (and define what these terms mean); it is not necessary to arrange such education in school. Schools are mandated to make 'reasonable adjustments' for the education of ill children. Liaison with medical professionals is mandated. Schools should, throughout, be 'working with and listening to the families as part of this process' (Annexes 5 and 6).

A recent report (Tymes Trust, 2015) showed that education was a 'serious concern in around 90% of our Advice Line calls'. So, there is legislation about the education of ill children; experience from patient groups and this report show that it is frequently not adhered to.

## **7. Negative impact arising from the lack of understanding of professionals**

This report shows that many children and their parents have great difficulties with diagnosis and with the school system in getting appropriate provision for their needs. Patient groups hear many accounts of inadequate and unhelpful responses from GPs and from school and social services staff (see Section 4 above).

Indeed, patient organisations know many instances nationally where the families of children ill with ME have been threatened with care proceedings and some have been threatened with sectioning. (Some young adults have been taken into psychiatric hospitals or care.) This has been reported in the press (Gillespie, 2014, *ibid*) and more recently on the Radio (BBC Radio 4, 2017). This is entirely unnecessary, damaging to ill children and their families, extremely stressful for everyone, and a waste of resources. It is essential to prevent this in Oxfordshire.

## 8. The Survey

Our short survey attempts to gather some systematic qualitative information in order to improve services in Oxfordshire. As part of its support function and to mark National ME Awareness week, OMEGA holds a tea party for parents and children and young people with ME who are well enough to attend. Following this event in 2013, a short survey was publicised to OMEGA members and put on its website and on the websites of the national organisations. This enabled a comparison of experiences in and out of Oxfordshire; we asked respondents to indicate which county they lived in, though not all did so. Following a letter in the *Oxford Times* in May 2015 (Annexe 7), five more surveys were returned. By July 2015 there were 28 responses (nine in hard copy and 14 by email). Most (18) were from a parent or family member of a child with ME, four were from children and six from adults who had had ME as a child. (Three did not give their county.)

	Oxfordshire	Out of Oxon	Not known	Total
Parent/family	8	9	1	18
Child/young person	1	1	2	4
Adult affected as child	3	3	0	6
Total	12	13	3	28

Two parents of children with ME also had ME. Five of the six adults affected as children were still ill as adults – at least two are severely affected. These six adults wrote at length about their experiences. This shows the severe and long-lasting nature of this illness in adulthood. Three children responded to the survey. These responses were all to the online survey and they did not give the county they lived in. We asked five open questions in order to find more about the lived experiences of young people with this illness. The replies varied greatly both in content and length. (See also Note 1 Research methodology.)

## 9. The Results

For some of the questions we have separated the responses of children, parents and those who had ME as children, and those from Oxfordshire and in other parts of the UK. Some respondents listed a few aspects under each question, and others wrote at greater length. Full transcripts are in Annexe 8 in the Dropbox. For Questions 1 and 2 we categorised the comments under the topics which emerged and have put all on the same topic together in the body of this document. Verbatim responses to Questions 4 and 5 (about schools and education) are in annotated form. We sorted comments by topic and noted how many there were on each topic. *All comments in italic in the body of this report are verbatim quotes.* This is a qualitative study, reporting

on personal experiences. (The number of comments on any topic may indicate how salient the topic is in the experience of respondents.)

## **9.1 What was helpful?**

**Q1. What has been most helpful in managing/coping with ME in your family (either your own illness, or that of a child or parent)?**

### **Oxfordshire parents**

In Oxfordshire eight parents responded. They said information about the condition was helpful; some comments said consultants were helpful and one said their GP had attended school meetings. Other things identified as helpful included the Community CFS/ME Service (which includes provision for young people aged 14 years and over only). Three said referral to the Bath service was helpful, one said this was only for diagnosis, one said they didn't offer anything they hadn't already tried. One said a psychologist was helpful. Other comments specified meeting other people with ME and the support of local and national patient groups and the Parent Partnership organisation (now called SENDIASS - Special Educational Needs and Disability Information, Advice and Support Service). Further comments said pacing and keeping a diary were helpful, and that the school and head of year were. Finally, some responses mentioned personal and domestic factors, including the support of friends and neighbours, the company of the pet dog and keeping a sense of humour.

### **Parents outside Oxfordshire**

For parents outside Oxfordshire, nearly half specified referral to a specialist centre as helpful: some to a community psychologist or to the help of a specialist OT (Occupational Therapist) and to the local CAMHS (Children and Adolescent Mental Health Service), CBT (Cognitive Behavioural Therapy) provision and to other services. Others specified a support group for parents as being helpful; complementary therapies and specific help from one of the national patient organisations (Tymes Trust, 2015, *ibid.*, p. 5) and their medical advisor were also named.

### **What children found helpful**

One had had *brilliant support from school*. One said they had a supportive family and the other said *being able to rest and being looked after and home-educated by my mother*.

### **What people who had ME as children found helpful**

Six survey forms were completed by people who had had ME as children, at least five of whom are still ill as adults. One is *housebound most of the time, trip out in a wheelchair roughly every 10 days*. This confirms that ME can affect people severely and can be a very long-term condition. There is a drastic reduction in the quality of life.

### **From Oxfordshire**

Most cited were home visits and support with applications for benefits and educational adaptations from the GP. Also, *doctors who listen and try and*

*understand and who are able to say, 'I don't know'. One respondent grew up in Oxfordshire, became ill at age 14, later moved to Buckinghamshire, remained ill and was only diagnosed at age 40. This person said the ME and Pain Management clinic at Rayners Hedge in Aylesbury was helpful, because it covers absolutely every aspect of coping with ME physically, mentally, emotionally and intellectually.*

### **Out of Oxfordshire**

A respondent in South Yorkshire identified getting a diagnosis in 1966 (sic) by a Paediatric Neurologist (Dr Peter Baxter at Northern General Hospital) who saw her/him regularly for three years. They were also referred to a psychiatrist to rule out mental illness (discharged after a 20-minute chat) and to a physio to prevent muscle atrophy. This doctor said that unless people got better in a year, *it tends to stick around*. (This also confirms the long-term nature of the illness for some patients [ME Association, 2015].)

Other things identified as helpful by this group included *private specialist neuro physio at home*, referral to Dr V. Patel, George Elliot Hospital, Nuneaton, access to antivirals and immunoglobulin and *specialists who helped diagnose co-morbidities not spotted by the CFS team I saw*. Several members of this group identified more personal factors like the support of friends and other sufferers' *support and understanding*.

### **Summary: What people found helpful**

- Some specialist teams
- Oxfordshire CFS/ME Service for those of 14 and over
- Diagnosis only at the Bath service (Oxon respondents)
- Support from patient groups, local and national, support groups
- Information about the illness
- Some GPs

In general, these comments show that it is possible to make appropriate and helpful provision for children with ME, and that patient support groups are helpful.

## **9.2 What was not helpful?**

### **Q2. What has not been helpful in managing/coping with ME in your family (either your own illness, or that of a child or parent)?**

#### **Oxfordshire parents**

Most of the negative comments from the eight Oxfordshire parents were about medical services. One said there was no clear diagnosis, four specified delays in referral, two that having to travel to the referral services was not helpful, three that the GP was unhelpful. A further six said hospital services were unhelpful (a psychologist, unspecified hospital, and the pushing of inappropriate CBT and GE [Graded Exercise])). One said the lack of transition (at 14+ or 16–18) was made worse by the lack of clear diagnostic criteria or a pathway of care. Three specified unhelpful responses from schools about

attendance issues, three had been threatened with care proceedings or sectioning. (See also Qs 4 and 5.) Disbelief, stigma and misinformation were specified in two comments: other people's attitudes and lack of respect, and the comment (from a professional) that the illness was *all in the mind*. One Oxfordshire parent said, *We have had to fight for everything*.

### **Parents outside Oxfordshire**

Parents outside Oxfordshire said the lack of a paediatric service and limited access, by phone, to the adult service was unhelpful. The general unhelpfulness of medical services was the most specified issue – one GP *did not believe someone of under 14 could have the illness*. One said *18 months to diagnosis* and that poorly educated paediatrician, GP, school nurse and psychologist were all unhelpful. One said, *No one believing us*. The difficulty with diagnosis affecting schooling is summed up by one Essex respondent, *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*.

### **What children found unhelpful**

All three responses from children commented on the unhelpfulness of their GP. One said huge lack of knowledge from GP and another ... *my doctor has no idea about this...* Another commented that doctors *as a whole would do simple tests, tell me I was fine and then send me home and I have consistently felt that however kind the doctors were, if it couldn't be solved with pills or antibiotics, they didn't have time for me*.

### **What people who had ME as children found unhelpful**

Many (five of six) respondents who had had ME as children were still ill as adults. One is *housebound most of the time, trip out in a wheelchair roughly every 10 days*. Respondents reported negative experiences about medical services, including a specialist CFS team (Bristol). Lack of listening and disrespect were also cited.

#### **From Oxfordshire**

One participant said it was not helpful to have *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*. Another said, *Being told I had mental problems because I got so depressed, which was actually a symptom of the ME*. Another emphasises: *Lack of listening from those who are assessing or treating*.

#### **Out of Oxfordshire**

One person mentioned health care professionals as being obstructive and *asking the carers to report back on my health and capabilities without us knowing*, which added to an already stressful illness. In addition, the tendency to psychologise the illness was not helpful for most of them: *Trying to prove it is not psychological and that I do not need to see a psychiatrist*.

Interestingly, the opinion of one GP that the CFS team physio *was unhelpful... in the approach of using a model that the illness is based solely on deconditioning and fear of exercise doesn't fit with his experiences or with research (quoted) in the USA.*

One reported that the school said s/he did not qualify for education at home. If this had been provided, s/he says, *I would have been able to save myself the awful consequences of forcing myself into school (then collapsing and being driven home after one lesson on several occasions) which may be partly why I'm ill nearly 18 years later.* The same participant reports that there was no pressure from the school to attend and agreed s/he could repeat a year – although *I ultimately dropped out, but I was 16 by then.*

Our members have noted that the prognosis may be just as serious if the illness is treated appropriately. *There is a risk of people thinking it is only serious if the patient does pacing wrong, that improvement is inevitable if you're 'doing it right'.* We have informal reports of young people and parents being criticised if the child's condition does not improve – a case of 'blaming the victim'.

#### **Summary: What was not helpful**

- Medical services, GPs (poor knowledge/training) and hospital services
- Lack of or delays in diagnosis and referral
- The assumption that depression is causal, when it is a consequence of illness
- Not listening to children and parents, and pressure on families
- The consequent effects on education: 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.

However, this is not always the case: *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.*

### **9.3 Q3. What would you like from a clinic service like the Oxfordshire CFS/ME Service?<sup>4</sup>**

This question was answered by more Oxfordshire parents (some of whom had been able to access this service when the child turned 14), than by those outside the area. There were also responses from four young people (mostly outside Oxfordshire). Most (15 comments) wanted practical advice on *living well*, improving *quality of life* and generally *managing the disease* and its

<sup>4</sup> Formerly OCCMET Oxfordshire Community CFS/ME Team. The service helps people from 14 years old.

effects. Some wanted advice on medication to help with sleep or pain, and supplements. Some wanted help with 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...* Where there is an ill child, family dynamics are affected; one heartfelt comment: *...especially fathers who often struggle with this diagnosis to the detriment of the child and marriage.*

Two comments specified a very *slow build-up* in activity was needed: *How to slowly and sensibly build up the amount of time one can do physical exercise per day and gradually and sensibly build up the amount of time you engage in mental activity.*

Five specified no psychiatric input in such a service: *No GET or no CBT as standard* unless it was helpful for another issue. However, one wanted counselling to be part of such a service.

Overall a number of respondents said any service should **listen to young people and their parents and believe them**. This is confirmed in communications from the national organisations and more formal reports (Tymes Trust, 2001).

A number wanted help and advice to contact other agencies about benefits, funding for a PA, access to aids and to *liaise with benefits agency for parents who have to give up work to become full-time carers*. There were nine comments about schools and education, including liaising with and providing information to the school, helping with special arrangements for exams, online education and home tutors, and explaining the difficulties young people have with cognitive function.

A comment from someone who had ME as a child: *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.* (These comments are considered further under Q4 concerning Schools and Education.)

The next most common requirement (six comments) was for contact with other patients and families and local patient support groups, although this is not universally wanted – young people have varied needs, as do adults. *X... is totally against speaking or communicating with any other young person with the same condition.* So, any intervention needs to take the individuality of the child into account.

In relation to medical services, five comments wanted such a service to provide training and information to GPs, several wanted early and correct diagnosis with other conditions ruled out. The referral pathway should be clear. 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>5</sup> (sic), a waste of everybody's (sic) time.*

<sup>5</sup> Primary Child and Adolescent Mental Health Service

Other comments indicated that such a clinic service should be the single point of access to other specialists for other conditions. Further comments said there should be no minimum age of access to such a service (children known to OMEGA have had to wait until a child's 14<sup>th</sup> birthday before they could be seen by the Oxfordshire CFS/ME Service), or that transition to adult services should be easier. See NICE Guidelines (NICE, 2016) Transition from children's to adults' services.

#### **Summary: What was wanted from a clinic service like the Oxfordshire CFS/ME Service?**

- Listen to and believe young person, offer practical advice
- Early and correct diagnosis
- Medication for sleep and/or pain
- Wider support for family
- Liaison/contact with other services and agencies e.g. Benefits Agency, schools, Social Services for funding for a PA
- No minimum age of access to a clinic service

#### **9.4 Schools: Q4. What can schools do to help students who have ME?**

The major themes in the responses to this question were: beliefs/understanding about the illness, working with parents and family, staff involvement (including tutors and nurses), peer involvement and support, supporting the child who is able to be in school and supporting the child who is unable to be in school.

##### **a. Beliefs/understanding about the illness**

There were seven comments from Oxfordshire parents and eight from outside Oxfordshire. Only one (1/15) of these was positive: *Our school... has been extremely good and supportive... they listened, understood and believed him.* (Oxon)

All the others asked for better understanding: *Schools in general need to be far, far more understanding about children who have ME. I was told by a headteacher that they had had ME and had pushed through it, suggesting that if my 10-year-old did the same, he would be fine.*

Other responses indicated very difficult attitudes from the school about the child's illness: *Stop blaming parents and Stop ridiculing or belittling the children who are ill with ME. This meant: Be much more understanding — this means educating the teaching profession on ME and what it means to be suffering from it.* Some indicated attendance issues: *Believe that they are ill and don't pressure for increased attendance too soon.* Also see **Supporting the child** below.

## **b. Working with parents and family**

There were five comments from Oxfordshire and four from outside. **Only one of these was positive (1/9):** *Her school has been very good and understanding* (Essex). All the others pleaded for schools to work together with families and listen to the child:

- *Draw up a plan of education, involving the parent.*
- *Listen to parents; we know our children and what they are able to manage on a daily basis.*
- *Listen to parents, who usually know their children best.*
- *... be led by the ill child, they know best – ask how they can be assisted. If they say they can't do it, they are right.*
- *Listen to them [child].*
- *Listen to the children themselves, and don't dismiss them as 'too young to know what they feel'.*

## **c. Staff involvement (including tutors and nurses)**

In this category, we had 12 comments from Oxfordshire (only two positive) and five from other areas (only one of these was positive).

### **Positive comments**

*They were keen to do whatever they could to help. Miss [X], [the] Head of Year, was particularly helpful and empathetic.* (Oxon)

*[The] nurse, paediatrician and psychologist have all been in to [the] school to educate them about this illness and what s/he needs from them, which is mostly understanding.* (Cumbria)

### **Need for training**

- *Train staff in recognising and supporting children with the illness (as they would for other conditions)*
- *Train staff and senior management team about ME*
- *Train their staff on details of this illness*
- *There was a call for training for school nurses: Ensure school nurses have training in ME* (Oxon)
- *Have school nurses who understand the condition* (Berkshire)

### **Need for communication**

*Tell teachers about the child's illness. In large schools, some teachers don't realise a child is ill and not truant or too lazy to hand in homework.*

### **Recognise the child as an individual**

*Be supportive, listen to the child and their parents, be positive and not negative. Every child is an INDIVIDUAL and should be treated as such, as ME has lots of different symptoms and not all children are affected by all symptoms or in the same way.*

#### **d. Peer involvement and support**

There were five comments each from Oxfordshire and from outside the county.

About half requested information and awareness for other students.

*Hold information classes for the healthy students about hidden illnesses and how CFS/ME affects people. Help fellow students understand the condition. Explain to other kids in the class/school what is going on, so the sick child doesn't have to answer 30 or more lots of '... why can't you get up in the morning?' when they do manage to get into school.*

Others wanted schools to facilitate the maintenance of peer relationships, with pleas not to forget the ill child.

*From time to time remind classmates that so and so is still part of the class... so that the student doesn't get forgotten. Educate [other] children and foster a caring and supportive attitude towards the suffering child; create buddy schemes.*

There were concrete suggestions: *Allow a small/quiet room to meet a couple of friends in during break and lunchtimes to keep friendships and socialisation skills alive.* Some combined both, adding that it can help other students in their social development: *It's important to educate the other children in the class realistically – the whole class can learn about being ill and how to be a friend.* Other references to peer support were in responses to Q5 (about education services, pp. 18 – 20 below). These said it was *important to maintain social activity and contact* and drew attention to bullying: *Other students need to be educated about this illness and other hidden illnesses so that bullying is reduced. They can be helpful and supportive if they have some idea what is going on.*

#### **e. Supporting the child able to be in school**

By far the largest numbers of comments were in this category (eight from Oxfordshire and 45 from elsewhere). Again, most of the comments and suggestions indicate that support from schools is unsatisfactory. However, a few do 'get it right' for children, so this *is* possible.

##### **Positive comments (all from outside Oxfordshire)**

*My [...] school have been supportive, we have regular meetings with them and s/he is on a part-time programme. S/he has a pass so s/he doesn't have to queue up for lunch.*

From a young person, *I couldn't have asked more from my school. They informed teachers, allowed me extra breaks, extended homework deadlines, rang me on days off, supported me through my exams. Maybe a better knowledge of the condition would be more useful.* Another young person says, *My school is great; they've cut down my timetable for me so I'm not in as much.* An adult diagnosed at the age of 14 says, *My PE teacher let me stay in the staff room in the sports hall and just left me in charge of the tin with everyone's watches etc. in; I always had a nap.*

## Specific suggestions

Many respondents asked that schools be more flexible about attendance:

- *Shorten their days.*
- *They need to be open to part-time timetables, however inconvenient it may be to the school. If there were more access to this, then it would be easier for young people to get back to school at a level which they could manage instead of perhaps having home tuition where they can end up feeling more isolated.*
- *Allow the child to go into school for a short time each day or once a week etc.*
- *Waive the usual rules about attendance/punctuality.*
- *Put aside attendance statistics.*
- *Schools need to reduce the workload burden in pupils and not expect them to catch up on work from missed days as soon as they return.*
- *Support the child's achievements instead of focussing on their attendance or non-achievement.*
- *Discuss issues regarding attendance in a respectful way rather than accusatory.*

In summary, this comment recommends education *based on their needs at home if necessary rather than using school attendance as the sole measure of improvement.*

### f. **Supporting the child who is unable to be in school**

Seven comments (from Oxfordshire and elsewhere) indicate that maintaining the child's contact with peers was important for our participants:

*ENSURE the student, no matter how ill, isn't forgotten, that he or she is kept in the loop with Newsletters and invitations to activities... even if the sufferer isn't able to attend, being asked and not forgotten is very important. Enable contact between the child and the rest of the class. Pass on messages and news, CDs, DVDs, Facebook, emails, phone – when the child can manage these. Communicate about events and activities the other kids are doing. Invite her to attend special occasions and continue to feel part of the school community. Someone should be assigned to ensure the ill child is not forgotten when school is planning social events such as the prom, leavers' day, trips and outings.*

There were many requests for education at home, home tuition, the NISAI Virtual Academy and pleas for schools not to *put pressure on the child returning to school, before they are able.* Finally, it is clear that there are serious consequences to children and families if schools do not make appropriate provision:

- *He tried to attend but kept collapsing so has had very little secondary education.*
- *We were told that [xx] education [authority] (sic) did not recognise CFS as a condition where a child would need home tutoring.*
- *He has had very little help and is most ill.*

### **Responses to Qs. 1, 2 and 3 that apply to schools and education**

#### **Questions 1 and 2**

In Oxfordshire three respondents specified unhelpful responses from schools about attendance issues, three had been threatened with care proceedings or sectioning. Four comments referred to unhelpful schools. One said: *Schools, as they don't have enough knowledge and are concerned with their attendance figures rather than supporting an ill child.* Another said, *school [is] harassing us.* The difficulty with diagnosis affecting schooling is summed up by one Essex respondent, *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.*

#### **Question 3**

There were nine comments about schools and education, including liaising with and providing information to the school, helping with special arrangements for exams, online education and home tutors, and explaining the difficulty young people have with cognitive function. A comment from someone who had ME as a child: *Strong support for education of children based on their needs at home if necessary* instead of insisting that they be physically present in school. These findings are confirmed by Tymes Trust; over 90% of calls to the Tymes Trust Advice Line concern problems with schools (Tymes Trust, 2015, *ibid.*). On the other hand, good practice is possible: In Oxfordshire, 'Wood Green School's director of learning communities, Mark Bonsell, said: "This is a great example of how schools can work with students and parents to enable the young person to overcome adversity and, in Zoe's case, achieve very good results.'" (Robinson, 2014, *ibid.*, about student Zoe Fabian)

#### **Summary: What schools can do to help students who have ME**

- Listen to and take seriously the child and family. Work with parents — do not blame them for the child's illness. Believe what families and children say.
- 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.

- 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.

## 9.5 Education services such as home tuition, pastoral care

### Q5. Have you any comments about education services such as home tuition, pastoral care?

Themes emerging from the responses to this question concerned access to home tuition and online learning.

#### a. Home tuition

Home tuition was generally welcomed by Oxfordshire parents with a number of provisos about the need for flexibility, and the need for any tutor to understand the nature of ME and how it affects the child.

*Helpful to provide focused teaching in particular subjects, but it does demand more cognitive energy as sessions are longer...*

*Home tuition can be a lifeline [but] should be implemented quickly, and the child's needs taken into account, e.g. half an hour's lesson twice a week with no reading or writing expected. Home tuition works as long as you have the appropriate subject tutor and they have a basic idea about ME.*

*We had two tutors who didn't believe in the illness. One we didn't keep on, one refused to go to my daughter in her bed. Over time we managed to educate this tutor and she did eventually become very supportive. A parent shouldn't have to do this. It's stressful enough having a child bedridden or very ill with ME.*

*I was given five 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. I was told this was the minimum that was allowed — I could not have shorter sessions as I was supposed to be 'building up'. 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.*

*We tried tutors and some were better than others, but all had no idea about ME so some would be put out if our daughter was not well enough to do the lesson when they had made the effort to travel to us. It was not always possible to contact them to let them know not to come on the day.*

Outside Oxfordshire home tuition was, similarly, a mixed blessing:

*In my experience, you have to fight for home tuition.*

*Don't insist on it lasting an hour when the child can only cope with 15 minutes.*

*Don't enforce a nine GCSE timetable on them.*

*Home tuition is imperative. One to one lessons are shorter and means less work is missed and it is easier to return to school.*

*It sometimes works well: Having an understanding, supportive home tutor can make a huge difference to pupils' lives. Home tuition was a lifeline and ensured I got a partial education I would otherwise have never gained.*

Though not always:

*Council providing one hour a week home tuition was ineffective as child achieved nothing. And: Crap. Tutored all of secondary school – I lack basic English skills.*

And, as in Oxfordshire, access can be a problem:

*We have been told that, whilst [xx] is entitled to home tuition during [the] illness, it cannot be provided by our local authority because they don't have the staff available. S/He is therefore teaching [themselves] on days s/he feels up to it, and we are teaching [them] what we possibly can, until such time as we can afford to pay a private tutor.*

#### **b. Hospital school**

Even with the changes under Hospital School provision in Oxfordshire<sup>6</sup>, it was not always useful to children with ME.

*I had to fight very hard with the hospital schools to get the right education for [them] at first and it was not pleasant and it caused my health to decline.*

*School consistently refused to refer our son to the hospital school even though his attendance was 20%. Hub workers had no understanding of condition and treated [them] appallingly, so s/he had to make a complaint against them.*

#### **c. Online learning**

Online learning was generally valued as:

*Virtual education is most 'energy efficient'. [X] was the youngest pupil to have online tutoring in Oxfordshire and s/he excelled at it. Online learning is invaluable in many ways, educationally and socially, as it allows a student to interact with other students and feel part of a group.*

But there are difficulties when the school doesn't recognise the effects of the child's illness: *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 she interacted during the lesson.*

<sup>6</sup> In Oxfordshire educational provision for sick children who cannot be in school devolves to the Hospital School system. Some education has been provided in locality 'hubs' which were only appropriate if children are well enough to get to them. [www.ohs.oxon.sch.uk](http://www.ohs.oxon.sch.uk)

This shows the unintended consequences of school staff's lack of knowledge about the illness.

**Summary: comments about education services such as home tuition, pastoral care**

- 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.
- 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.

## **10. Conclusions/findings**

The findings are mixed, but the consequences of poor practice, for children who are 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 causing a life of illness and disability. Believe them and their families when they say they are ill. Early and correct diagnosis 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 (see Section 9 Results above).
- Children can become more ill or have a relapse after being made to do more than they are able. This is consistent with clinical evidence 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. (See Section 5 History above and Note on Treatment below.)
- 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 legally obliged to provide. (See Section 6 Legislation above.) These are 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.

## 11. Recommendations

1. Training for GPs in diagnosis and appropriate advice for young people.
2. Extension of the Oxfordshire CFS/ME Service to treat young people under 14 years of age.
3. Monitoring of adherence to the appropriate Statutory Guidelines in schools.
4. Extension of existing good practice in the provision of appropriate education to all schools. Training for schools about ME/CFS and its effects.
5. More training for School Nurses.

## Notes

### 1. Note on Treatment for ME

There is no known cure for ME/CFS (also known as CFS/ME, the umbrella term for several different conditions (Hutchinson, et al., 2002). Many children and young people (as in our survey) are and remain severely affected into adult life; some recover to some degree, but many are left with permanent disability, including those who become housebound or bedbound.

Previous claims for the efficacy of CBT (Cognitive Behavioural Therapy) and GE (Graded Exercise) as treatments for the illness are now discredited (*Journal of Health Psychology*, Vol. 22, No. 9, 2017) and indeed the NICE Guidelines (2007) are now under active review and revision. As in other illnesses, e.g. cancer, some patients *may* find pacing, time management or CBT (when given to help the patient adapt to their illness) helpful in managing the illness.

The evidence in this report shows what young people and their families find helpful from medical (and other) services. What doctors can do is provide timely diagnosis, medication for symptoms, information, family support, liaison with other services and agencies to help with access to practical and financial assistance; and above all listen to and believe the young person and their family. This is supported by Dr Nigel Speight (Medical Adviser to TYMES

Trust, the national charity for childhood ME): *stop looking for "treatment". If there was a cure we would all have heard of it. Just ask for diagnosis, sympathy and support!* and adds: *... doctors can... provide... protection... symptomatic treatment for pain, insomnia etc.... liaison with school... and... support for benefits.* <https://spoonseeker.com/2018/01/21/the-nice-guidelines-starting-again/>, 22 January 2018.

## 2. Note on research methodology

This survey describes evidence from a small sample yielding qualitative data. 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 echo the 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.

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## **Annexes**

All the documents listed here are available in the shared Dropbox folder [www.dropbox.com/sh/jdp172a1wrlywqj/AAAr2HvgiUJ6mEPET0PD\\_mFva?dl=0](http://www.dropbox.com/sh/jdp172a1wrlywqj/AAAr2HvgiUJ6mEPET0PD_mFva?dl=0)

Annexe 1: International Consensus Primer for Medical Practitioners

Annexe 2: Estimated numbers of children with CFS/ME in Oxfordshire

Annexe 3: International Paediatric Primer ME/CFS Diagnosis and Management in Young People

Annexe 4: OMEGA Campaigning Newsletter 2009

Annexe 5: Ensuring a good education for children who cannot attend school because of health needs Statutory guidance for local authorities 2013

Annexe 6: Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England December 2015, 2017

Annexe 7: Letter to *The Oxford Times* May 2015

Annexe 8: Full transcripts of verbatim responses

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