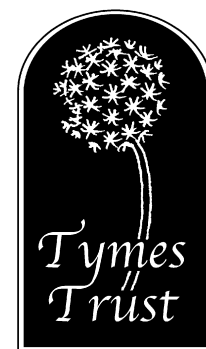


Professional Guides

ME/CFS Guidelines for Educational Psychologists



Naomi Burgess

Chartered Educational Psychologist

MSc Ed Psych C Psychol AfBPsS

Jane Colby

Former Head Teacher

Member, National Association of Educational Inspectors, Advisers and Consultants

Executive Director, The Young ME Sufferers Trust

Member, Chief Medical Officer's Working Group on CFS/ME

Abstract

An Educational Psychologist can be key to the provision of suitable education for pupils with ME/CFS. These guidelines will help you assess their needs and make appropriate recommendations.

The Department of Health now refers to this condition as CFS/ME

Many doctors use the term CFS (Chronic Fatigue Syndrome). Others prefer ME (Myalgic Encephalomyelitis) as originated in The Lancet.

This guidance concerns the neurological condition classified under the names ME and CFS by the World Health Organisation as a disease of the brain and nervous system (ICD 10; G93.3)

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Assessment of pupils with ME/CFS

Up to 25,000 children and young people are thought to suffer from ME/CFS in the UK. It is the biggest single cause of long-term sickness absence from schools.

Introduction

In January 2002 the Report of the Chief Medical Officer's Working Group on CFS/ME, published by the Department of Health, made the following points:

- It is a genuine illness and imposes a substantial burden on the health of the UK population. CFS/ME affects many people and their families in the UK and elsewhere in the world.
- Symptoms suggest dysfunction of the central nervous system.
- Common symptoms include persistent/excessive tiredness or fatigue; cognitive impairment; postexertional malaise; pain; sleep disturbance; recurrent sore throat; digestive disturbances; intolerances eg of certain foods, medications and alcohol; other symptoms apparently related to neurological and/or endocrine systems.
- Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of the symptoms.

Symptoms may include:

- Neurocognitive: loss of attention, concentration, and short term memory (verbal and numeric); nominal aphasia; speech production difficulties; inability to take in written/spoken information.
- Emotional: mood disturbance; irritability; depression.
- Sensory: hypersensitivity to sound, light, smell, touch and texture; intolerances leading to physiological reactions to some chemicals

(solvents, adhesives, cleaning products, perfumes etc); blurred or distorted vision.

- Balance and coordination difficulties: dizziness; wobbliness; vertigo; perceptual distortions affecting balance; fine and gross motor problems.

Research now shows that ME/CFS involves significant physical abnormalities of brain and body. This is no psychological illness. The severity and course of the illness varies. Although most children are likely to become significantly stronger over the course of time, some may require hospitalisation during their illness, some are affected severely enough to qualify for state allowances, and some need wheel chairs. At the time of writing these guidelines, there is still no definitive cure.

Doctors may recommend a variety of interventions to try and help the child and family cope, and to try to promote recovery. There are vast differences in response to these interventions; some treatments have been known to lead to deterioration in the child.

The difference in response to interventions is likely to be due a combination of factors. ME/CFS is known to be a heterogeneous condition. Therefore, factors such as individual pathology, severity and stage of the illness will all determine the effect of any particular therapy.

Evidence is, however, clear that rest and appropriate self-management, avoiding mental and physical over-exertion, are vital components to prevent deterioration and promote healing. In some cases, minimal mental or physical effort can be deleterious and the child

must learn to accommodate this during what may be a long process.

You are likely to come across, or to see some of these children for advice, or assessment. The notes below are intended to be a guide in supporting you with this task.

The Young ME Sufferers Trust has also published succinct ME/CFS information and professional guides for teachers, SENCOs and medical professionals, which will be of additional help. These are to be found at www.tymestrust.org/publications.htm.

The statutory guidance *Access to Education for Children and Young People with Medical Needs* indicates that schools are expected to have a designated member of staff responsible for children with medical needs, along with a policy for these children.

Schools are also responsible for producing an access plan in relation to disability, which should contain details regarding the curriculum, policies and procedures. It is expected that school buildings will be made accessible to children with disabilities.

Purpose of the assessment

Whether your advice / assessment is requested at School Action Plus or for a Statutory Assessment, you will need to provide Evidence and Guidance.

Your evidence will need to indicate how the individual's ME/CFS affects their:

- cognitive and learning processes
- learning and achievements in school
- emotional and social life

Your guidance will need to give an indication to the school/LEA, the child and their family, and perhaps also the medical services, the optimum way of managing the young person's Education in the context of their disability. Education may not always mean schooling. It involves:

- Day to day learning programme / its delivery, at home, at a unit or in school

- Physical Needs in whichever educational base
- Emotional, Social and Personal Needs
- Short term and longer term needs
- Short and longer term goals

This can be particularly tricky around times of school transition, Key Stage Changes, and National Examinations. Issues of funding may need to be clarified in relation to transition at 16.

Students with ME/CFS may not, in practice, be able to take up their entitlement to free Post-16 education without special provision. For example, although Further Education Colleges may suggest that they provide open access, the reality is that some students are unable to secure a place, where their medical needs determine that they require continuing home tuition. This is where distance learning or virtual learning schemes come into their own.

Planning the assessment

What you need to consider:

- Time of the assessment - maximum brain arousal may, for example, be during the afternoon. In survey results (the Trust's 2005 report *Our Needs Our Lives*) 75% of families expressed a preference for afternoon appointments whereas none preferred mornings.
- Venue with client and parent - the home is less likely to produce relapse or deterioration as no effort is spent on getting to the venue. If the venue is to be an office, make sure it is on the ground floor or accessible by a lift and consider the need for (eg) low light levels, low noise levels, reclining chair pointed away from the window, availability of a snack and a drink.

- How much time the young person can manage in one go - you will also need to seek information from the family about the effect on the illness that your interview has produced, after the classic latent period has elapsed, typically between one and three days. This will very much affect your recommendations.
- The best ways of collecting the information that you need.

Carrying out the assessment

Be prepared. Ask the young person / parent to:

- Fill in a questionnaire prior to your interview (a suggested questionnaire is appended to this document). You will need to explain that this can be filled in over a period of days to avoid effort overload and the feedback you receive over how long it took and how the child felt at the time will be valuable information.
- Keep a weekly timetable of the child's illness prior to your interview.
- Comment on their own performance eg what difficulties they experience in learning; what they find helps.
- Partner you in formulating the most appropriate and flexible plan.
- Let you know if the child begins feeling unwell during the interview, so that you can immediately stop and carry on after a break, or at a future date. You may notice the child's face blanche (become very white). The child is likely to feel ill around 20 minutes after this, even though they may not yet feel ill. It is advisable to stop if you notice this effect.

What you need to know about children with ME/CFS

Each child is an individual.

Each child with ME/CFS has their very own set of needs, just like children with other types of special needs.

There is no 'normal' example. Each case differs in its mildness or severity and possibly also in its pathology, depending on the criteria used for diagnosis.

When gathering your evidence from other professionals please remember to ask whether the professional's experience of ME/CFS is 'general' or 'specific' to this child.

Each individual's set of needs is always in flux, so

regular monitoring and fine-tuning of provision is also essential.

Disturbed circadian rhythm is a typical source of difficulty and is likely to be due to dysfunction in the hypothalamus. This is not often easily amenable to correction, so should be accommodated to allow time to correct itself during the healing process.

Succinct information on how ME/CFS affects a child's needs in school is at www.tymetrust.org/pdfs/teacherinfo.pdf.

A brief summary of symptoms and effects of the illness can be found at www.tymetrust.org/pdfs/quicktour.pdf.

The learning context

Remember that you are assessing the child to advise on their learning, their social, and possibly also their emotional needs, and their most appropriate learning context.

This context may be the home, a unit, a hospital, a school, or indeed, some combination of the above.

Please remember that you are advising on their Education, not necessarily their schooling, although schooling may figure in their education plans. Effectively you are helping identify their 'barriers to learning', and in so doing making recommendations to ensure that the child has access to education and its associated services.

Timescales

Except for the very severely ill, most children and students with ME are able to make some progress academically if education is suitably modified. However, they may be unable to follow the usual timescales for Key Stages, SATS, examinations etc.

Therefore please plan for the long term, so however long it may take, all their objectives, if realistically planned, can fit together like a jigsaw. Short and long term goals should be the product of 'joined together planning'.

Content of curriculum

Typically, the number of subjects studied at any one time needs to be reduced. This:

- preserves health
 - promotes recovery,
 - reduces likelihood of failure and attendant negative experiences
-

Stamina and how it may affect examinations

A child with ME/CFS can become exhausted quickly, with resulting malaise and possibly relapse. This can mean that tasks undertaken in school, school tests, or national examinations will be subject to falls in performance between the beginning and end of a task. Considering how best for the student to take examinations, it is advisable to ask for rest-breaks rather than simply a block of extra time at the end. It may be necessary to ask for both. Other related considerations are:

- A potential need to allow snacking during an examination to avoid a drop in blood sugar making the child ill.
- A potential need to reschedule the start time, since ME/CFS patients typically have a best and a worst time of day.
- A potential need to use the home as the venue for the examination, to maximise the effort that can be used on working rather than travelling; the aim of special arrangements is to level the playing field as much as possible for those who are disadvantaged, so that they may display their best work.
- Whether you need to apply for consideration of coursework marking, especially as a low coursework grade can put a ceiling on examination marks.
- Whether or not their examination preparation is disrupted by illness.

- Performance and health may be affected for an extended period (days or even weeks) after an examination.

Points to be aware of:

- Some schools separate the task of organising Special Arrangements from that of Special Considerations, so please be careful that this is considered from the outset.
- Requests for consideration regarding coursework marking must be made at the time or within a very small amount of time following the submission of the work.

The Guidance from the Joint Council regarding examinations changed substantially in 2005 so please ensure that you are aware of what the school can now do, and is proposing to do.

NB

- It may be advisable that SATs are not taken, in order to avoid disruption to the child's recovery and thus to the possibility of success in examinations conferring qualifications, which should receive priority.
 - It may be advisable to avoid mock examinations and have some simple practice sessions that are not so demanding on time or energy, as mocks can disrupt recovery and militate against achievement in the real examination.
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Assessment content

The Learning Questionnaire provided can be used as the basis for your assessment.

There are two elements to be considered in assessing a child with ME/CFS:

- Learning and achievement
 - How the child/ student views themselves and their needs
- It is possible that the child has areas of cognitive or neurological dysfunction affecting functions such as:
- short term memory and concentration
 - information processing
 - mental/abstract operations
 - writing (composition and transcription)
 - oral and aural and visual perceptual skills etc

Different types of difficulties may be more evident at different ages, in terms of curriculum demands (see Content of curriculum, above).

Do remember that in a child who already had learning needs, those needs are likely to have become exacerbated. This could, for example, apply to those with literacy acquisition difficulties - developing phonological skills, or for those with dyspraxic difficulties – development of fine-motor coordination, etc.

It is important to note where the child is in relation to their Key Stage, the exacerbation of any difficulties, and how their current difficulties are affecting their learning. There is no definitive approach to take, or test to use. It may be helpful to look at their attainment levels and you may find some sub-tests on cognitive tests useful, especially if the child is able to talk through any processing difficulties. It can be helpful to compare mental arithmetic with mechanical arithmetic or to observe the child tackling spelling, sequencing, or memory exercises. Many of the children you see will be able to tell you what they are like now compared with pre-illness.

You may be able to use their Record of Achievement/Progress (ROA/P) to get a measure of how they are achieving in relation to their Key Stage, which could be helpful to you and the child. However, where children have missed school and not been granted a home tutor or home-based course, this baseline information may not be available. It can also be

upsetting to over-emphasise the lack of progress that a sick child has been making – if more progress might be possible with a different or more supportive strategy, this is a helpful point to mention, remembering that health comes first.

If you need to do any assessment, some children enjoy the opportunity to show their skills and others are nervous; it is important to try and make sure that the assessment itself does not adversely affect their health. You may need to make a second appointment to avoid doing too much on one occasion.

When and if you feel you need to do further assessment, there is no definitive approach to take or test to use. Some children may be able to tell you what they are like now, compared with how they were before their illness. Others may have been ill so long that they will not remember and it is wise not to labour this point. Extreme sensitivity is necessary in discussing this subject as such comparisons can be distressing. Some children may like to do short subtests or curriculum based/criterion referenced academic exercises, which may help you and the child understand their processing difficulties. Talking to a child with ME/CFS, and observing how they are able to answer your questions, gives a fair indication of some processing difficulties.

However you proceed with your assessment, the child's comments and reflections on the process will give you insight into the difficulties that they are experiencing and help you plan.

Information technology

At the time of writing many Local Education Authorities are up and running with interactive technology for children out of school, and access to virtual learning is central to the current Government's initiative on Personalised Learning. So whilst LEAs are at different stages of development, it is likely that some usage of computer communication will be available and so it is important to remember to check the students' suitability for different types of IT.

The child may need a filter for glare, they may need to learn keyboard skills and you will need to determine

the most appropriate learning method – software typing skills packages are generally as effective as a keyboard course and may be the preferred method. If there is a central SEN IT provider within the LEA it will be worth liaising.

NB

Nisai Education and The Young ME Sufferers Trust have a partnership in delivering online interactive learning. For details see www.tymestrust.org/pdfs/succeedingwithme.pdf.

Reminders about sensory difficulties in ME/CFS

Light Photophobia - this can be aggravated by some sorts of lighting ie fluorescent lighting; the child may also need blinds down on a sunny day and may also need to wear a shade and/or dark glasses.

Sound Hyperacusis - sound can be very painful to sufferers eg children moving chairs across the floor, school bells and buzzers, the hum of fluorescent lights or air conditioning and certain types of music or musical timbre.

Heat Temperature regulating mechanisms are often awry in ME/CFS; tachycardia (racing pulse) may be experienced due to overheating, as may faintness, dizziness, uncoordinated breathing. Whilst these symptoms may resemble panic attacks, they are more usually due to dysfunction in the brain.

Smell Heightened sensitivity to smell may include perfume, fumes from cleaning agents or chemicals, disinfectants, paint; headache, nausea and dizziness can result from exposure to normal levels.

There may also be acute sensitivity to touch.

Some chemical/food intolerances may develop.

Flexible planning - short and long term

Health needs must always come first, since relapse typically results from over-exertion, and both school attendance and work demands are key causes of relapse from ME/CFS.

The needs of each individual child are changing all the time and there should be continual observation/reflection so that everything is continuously fine-tuned. The young person needs to know this too, so they understand the emphasis is on progress and process not simply achievement.

Keeping a simple chart record of daily/weekly routines, together with the fluctuations of the illness, can be combined with any diary-keeping suggested by the paediatrician. This may reveal the effects of particular activities; it will be useful to you, and to the medical and educational professionals involved in the child's care.

The young person's level of functioning may vary at different times of the day and different parts of the week and the chart may show this up eg:

- Are afternoons better than mornings for this particular child?
- Does the child need to recuperate on a Wednesday, and take a break mid-week?

This type of knowledge can be essential for any weekly plan either for the child going to school or a tutor visiting the home, and setting work etc.

Try using a six-weekly or half term timetable record and see how any learning targets fit into the pattern.

Always plan for less, rather than more, but leave your options open. We are informed that research now indicates that sufferers should only be working at activities that take up around 50% of their available energy. Ideally, not only should tasks be well within the child's energy envelope, they should also be broken up into small time units.

A year plan can help older students to have a longer term perspective on their progress, as well as ensuring the LEA has time to put provisions in place.

Feelings and attitudes about chronic illness

A sensitive but important area of any assessment is a discussion of the young person's attitude to chronic illness and what they feel will help them in living with illness. It is useful to have a similar discussion with parents. There isn't a right or wrong answer, just a process, which can hopefully be identified.

As a result of the illness, children may or may not suffer with varying degrees of depression and/or problems of general anxiety. In many cases this is misunderstood, as if the symptoms are the illness, rather than resulting from it. Such feelings may develop from normal frustration, such as anyone would feel if their health and life were seriously affected, but may also be due to chemical abnormalities within the brain.

You are likely to find diverse views about treatment of these symptoms amongst doctors and therapists as well as among young patients and their families. However, remember that many symptoms, for example, distress and weepiness, can often result from

simply doing too much and a reduction in demand can help.

It is not necessary to refer the child automatically to Child and Adolescent Mental Health Services, but only if you feel that this particular child may need such support. A recent survey by The Young ME Sufferers Trust revealed that few families wish to be automatically referred to mental health services any more than they would wish to be referred there for any other organic illness.

It is always worth asking, and recording, the views of the family, answering what questions you can and making referrals if requested. It is, however, universally helpful to identify practical solutions; for example, it is possible to tackle isolation in such a way that the child's health is not threatened (ways in which friends and school can keep contact with the child who cannot attend) and to find practical solutions to other problems in a similarly pragmatic way.

Many secondary schools have school counsellors available, or a school nurse or a learning mentor. For professional counselling it is important that the child sees a properly qualified and supervised professional, but useful additional support can come from these other sources too. It is important that such professionals understand that ME/CFS is an organic illness, not a psychological condition, even though some of its effects may result in psychological distress.

You may find it helpful to use a structure such as a self-image profile as a way in to discussing self-image and feelings. Whatever tool is used, it should be carefully chosen for its appropriateness and used in a sensitive manner.

Children who are ill are usually desperate to try to restore some semblance of normality and school routine to their lives, and often try to do too much. They often relapse with the amount of effort they make. So remember to advise against overload. They need to learn to understand the limitations their illness

places on them, and simultaneously be pleased with any success.

It can be more productive to ask them how they feel about achievement rather than recommending a strategy to reinforce achievements. There is still much discussion about the use of cognitive behaviour therapy, which is difficult to evaluate due to problems with sample selection, assuring uniform delivery, and failure to account for reasons of those who drop out. Families may welcome the opportunity to speak to you as a professional about the issue of CBT. Used insensitively, and by those who do not understand the physical limitations that ME/CFS can impose, it can lead to children setting or being set highly unrealistic goals, which can be positively damaging to their health and self-esteem.

It is important that we do not set children up to fail, either in their education or in managing their illness, but instead, structure their situation such that they have the best chance to succeed and to see an improvement in their health.

Special notes on young people in year 9 and older

Whether a child has a Statement or not, planning and transitional planning in year 9 is vital.

- You need to plan flexibly around GCSE Options.
- You need to think about Special Examination Arrangements.
- You need to consider the most appropriate 16+ provision.

In line with Code of Practice January 2002 children with long term illness, with or without a Statement of SEN, will need the involvement of a number of crucial Agencies. This is likely to include Health, Education, Social Services where children may be entitled to disability provision, and with involvement of Connexions in whichever guise it may appear.

Links will need to be made between school and Further Education/Higher Education. Direct contact can be made with receiving institutions in FE or HE. With changes envisaged under the Children's Act 2004 and Every Child Matters, links between agencies and departments may become easier to negotiate. However, issues of confidentiality of information have been raised. Disability legislation should help ensure that all children and young people with ME/CFS are able to receive their education in a manner appropriate to their needs.

Places on Nisai Education's free Post-16 virtual education courses for students with ME/CFS are currently available for members of The Young ME Sufferers Trust.

Medical recommendations

It is important to remember that a General Practitioner is a qualified doctor who diagnoses and treats medical conditions and a recommendation from a General Practitioner to reduce demand on the child - for example, a suggestion that teaching in the home should be considered - is as valid as one from a consultant paediatrician. The Exemplar Megan's Journey shows home tuition and other modifications being granted by the LEA upon the request of Megan's GP.

Government statutory guidance Access to Education for children and young people with medical needs states that obtaining a recommendation from a paediatrician is desirable, but this is not a statutory requirement. It cannot be, since provision must be made for children unable to attend school once three school weeks have elapsed. An appointment with a paediatrician is normally only available this quickly in emergency situations. It may therefore constitute a breach of statutory obligations to wait for a paediatrician's recommendation.

Further reading

Government documents to which you may need to refer :

- *DFES Guidance 2001 - Inclusive Schooling*
- *DFES Guidance 2001 - Access to Education for children & young people with medical needs*
- *Special Educational Needs and Disability Act 2001*
- *DFES Guidance 2001 - Promoting children's mental health within early years and school settings.*
- *SEN Code of Practice 2002 - Medical Conditions*
- *Accessible Schools Planning 2002*
- *The Children Act 2004 - Every Child Matters*
NB The Children Act 2004 provided the legal spine for the Every Child Matters : Change for Children programme, which is designed to support those working to improve outcomes for children and families.

Other helpful publications :

- *Young Hearts* (www.tymestrust.org/pdfs/youngheartsflyer.pdf)
A collection of inspirational poetry by over 40 children and young people with ME aged 7 to 26 with a foreword by Terry Waite CBE. This book was originally the dream of Tymes member Jade Louise Scarrott who was so tragically taken from us in a road accident at the age of 14. She wanted to raise awareness and understanding of ME in children. A review (www.tymestrust.org/pdfs/yhrefview.pdf) was recently published by Special Children magazine. All profits are used for the Trust's services.

Available online at www.tymestrust.org/tymespublications.htm :

- *Succeeding with ME*
The "virtual classroom" and its relevance to pupils with ME
- *Professional Guides - Teacher Information on CFS/ME*
A two-page guide
- *Professional Guides - Back to School?*
Interpreting government guidance
- *Professional Guides - Pushing the Boundaries in ME/CFS*
Physical evidence for pupils' needs
- *Professional Guides - Implications for Schools of the Chief Medical Officer's Working Group Report on CFS/ME*
A one page guide

Disability discrimination law

Disabled children's education is now covered by disability discrimination law. The following excerpt is taken from a letter to a school from the Disability Rights Commission.

We have been consulted by [Child X's] father about the problems she is having in attending some of her A level classes at your school.

The Special Educational Needs and Disability Act (SENDA) 2001 amends the Disability Discrimination Act (DDA) 1995. A disabled person is discriminated against if:

- *A responsible body treats a disabled child less favourably, for a reason relating to the person's disability, and that treatment cannot be justified or*

- *A responsible body fails to make a reasonable adjustment and a disabled child is placed at a substantial disadvantage, and that failure cannot be justified.*

[The letter here goes into specifics of the case.]

If it is not possible to resolve the situation informally or you feel it would be helpful to have the assistance of a neutral third party, we could refer this matter to the Disability Conciliation Service. This is an independent service to which the Disability Rights Commission can refer cases. I enclose a leaflet for your information. They would assist the school and the family to find a solution which satisfies everyone.

Failing this it would be open to Mr [child's father] to take a Disability Discrimination Act claim in the Special Educational Needs and Disability Tribunal.

Notes

- 1 A written opinion had been sent to the family indicating that their child was likely to fall within the definition of a disabled person in Section 1 of the DDA.
- 2 They had brought their case to the attention of the Disability Rights Commission because the headteacher had, atypically, refused to sign the Tymes Trustcard or provide an alternative. The card is provided by The Young ME Sufferers Trust, backed by medical diagnosis, with the aim of protecting the health of children with ME in school. The carrying of the card has been endorsed by the Secondary Heads Association and

Education Minister Baroness Ashton and strongly recommended by Lord Clement-Jones CBE, as Liberal Democrat Spokesman on Health in the House of Lords.

- 3 The previous year the same family had been able to obtain home tuition only after taking High Court action. Such legal wranglings are obviously undesirable and stressful for all parties and the Trust considers that one way in which such actions can be minimised is through a good understanding of this medical condition on the part of educational psychologists, who are key personnel.

One family's experience

I want to tell others about my experience with school, the education department, two different educational psychologists and what happened to my son, who had already had ME for over 3 years by the time he was 14 years old.

Unlike most parents, I had a lot of experience with ME as my husband had been coping with it for 7 years. Despite this, it took my doctors - and me - over a year to admit that this is what my son Matthew's symptoms were.

In my heart I felt it was ME but my head just couldn't accept that this could happen twice in the same family. †

The consultant also couldn't accept it. He thought my son was just copying his dad's symptoms. Thankfully, our GP did believe him and with his support the education department accepted it too.

After several meetings with the educational psychologist, I thought we would never get a home tutor, even though Matthew hadn't attended school for 6 months. But at this time the psychologist retired and then things began to move.

I was left in the hands of the school. The Principal had first-hand experience of ME as his own daughter had missed 2 years' schooling due to ME.

The Deputy Principal, with whom we mostly dealt, also had experience of the illness, in that he had a friend with ME. In fact, most of the teachers I dealt with were empathic to my son's condition, which was a big relief for me, because I knew that others had experienced the exact opposite, and I had heard of parents being taken to court by Local Education Authorities.

In my mind, I prepared for this, thinking that I would move town if things got that bad, because I didn't think I could go through all the stress that would lead to. I was having to make all the family decisions, meet with psychologists, consultants etc and trying to look sane, rational and as if I'd had a good night's sleep! Looking after a young person suffering from ME is time-consuming and exhausting, and broken nights are commonplace.

As a meeting with the new educational psychologist approached, I was dreading what I expected to be more stress and pressure to prove that my son was ill and not school phobic. However, after the very first meeting we were given a home tutor, for 5 hours a

week. He was the only professional who asked me 'How are you coping?'

The home tutor, who had no prior knowledge of ME, was very supportive, gently trying to build my son's confidence. The school set up a programme under which he could go into school any afternoon when he felt he could manage for one period. He didn't need to wear the school uniform and he had control, with no reproach if he couldn't make it.

However, he only made it to a few classes. He was unable to continue with the programme, so the tutor came out to him. Sometimes he wasn't well enough to do much work, so the tutor talked to him and encouraged him, and by the time she left his spirits had been lifted. Over a period of five months they worked on a project compiling a remote control catalogue, which was quite an achievement for them both.

I realise that not all families have been as fortunate as we have. A lot of parents have, and still are, battling with Education Authorities that unfortunately do not have full knowledge of ME.

I would urge families to try and explain and to give out information from reputable patient organisations - as recommended by the Department of Health - particularly The Young ME Sufferers Trust, which specialises in the education of children with ME and works in partnership with Warwickshire LEA on the Nisai-Iris project, which has now gone nationwide.

What ME pupils need is unconditional support. Their health must come first. If the teachers at my son's school hadn't experienced ME first-hand, perhaps they wouldn't have been so understanding.

So I'm writing my experience to let other parents, children, teachers and educational psychologists know that our own experience has been positive, and that it is possible to break through the mistrust and the stigma that has been associated with ME in the past. There is light, understanding and empathy at the end of this soul-destroying tunnel.

Note

I would like to commend the Trust's magazine as a lifeline for parents, telling them what to expect and where to get help. Many times I was at my wits' end and the magazine would come in the post with an experience reflecting mine. Just to know that we weren't on our own was uplifting.

† Clusters of ME/CFS are common in schools, communities and individual families, thought to be due to an infectious trigger to which other people mount a satisfactory immune response. This mirrors the pattern of other diseases of infectious origin.

Use of the questionnaire

This questionnaire will offer you a structure for the interview. It is designed to be passed to the family before you meet them.

If the family fills this in first, you may well be able to plan better, the meeting may take less time, and the family will have more of an idea of the approach you will take. This is important because many families are naturally apprehensive about what the EP will want to do, and about whether their sick child can manage it. It is very easy to make a child with ME/CFS worse. Concerns may include:

- Judgements you may make about their own care of their child;
- Judgements you make about their relationship with the LEA or the school;
- Whether you understand enough about the illness to be sensitive to their child's needs;
- Whether you will consider that their child's illness could be due to a family dysfunction;
- Whether they and their child will feel reassured after your visit/assessment or left in a state of exhaustion or anxiety.

You will need to negotiate carefully with the family about the time of your meeting, as children with

varying degrees of ME/CFS function better at different times of the day, and may have restricted windows of time. They may also have better or worse days of the week, depending on their weekly activities.

Expectations will be affected by professional attitudes already encountered, read or heard about, including cases which have been mistakenly diagnosed as Munchausens Syndrome by Proxy / Factitious Induced Illness or Pervasive Refusal Syndrome, with all the attendant consequences.

In the section 'About School' there is a question about SATS and examinations. The Young ME Sufferers Trust recommends that pupils with ME do not generally attempt SATS as working for these tests can worsen the illness without conferring a qualification. The principles are that energy should be saved for healing, for essential work, and for making life worthwhile. Of course some pupils actually like to do SATS and want to do them.

It is important to remove any burden of anxiety (find out how the child feels about exams). Flag up and talk through support mechanisms like special examination arrangements.

Secondary age children - project and coursework

In relation to the question about project work and course-work, the Trust encourages families to discuss and negotiate. Coursework for pupils with ME/CFS can be considerably reduced so that they only do the minimum required by the Exam Board. It is important that you note this base-line information, which will

ensure that the most suitable and flexible ME-friendly arrangements are made, so as to facilitate a true reflection of the pupil's ability. Some families will already have very well organised systems in operation, but it is our experience that there is a huge variety of schools and school practices.

About school

Some of the questions in this section are meant to help elicit information about situations in school where pupils have found it difficult to negotiate a suitable alternative for a standard activity, or an approved method of excusing themselves when they need to, along with a suitable place to rest. If, for example, they feel faint in a class and there is a cover teacher who doesn't know them, how should the pupil deal with this?

What system might be in place for them to facilitate flexible opting in or out? Generally it is not recommended for children with ME/CFS to be in PE/

exercise sessions. In cases where, over time, children have recovered sufficiently and are now strong again, they might like to be involved in some gentle, non-demanding physical activity during the day-time. However, it must be borne in mind that exacerbation caused by physical exercise is a diagnostic factor for ME/CFS and great caution is needed. Children can be over-optimistic about what they can manage and a relapse is always to be avoided where possible. The maxim "better safe than sorry" is highly appropriate here.

Timescale

The questionnaire will be needed by the family for some time beforehand. It gives them something positive to do in the run-up to the meeting. They need to understand that parents can read it to the pupil and also do the physical writing of the answers where

necessary. It must also be quite clear that it can be completed in easy stages over time, to minimise adverse reaction caused by overwork on any one occasion. These points are mentioned on the questionnaire itself.

Learning questionnaire - ME/CFS

Note to parents

My name is _____ and I am your child's Educational Psychologist.

Answering these questions is meant to help us understand how much your child can manage to do within the limits of their illness. It can be done in stages over a number of days if necessary.

For the pupil - read this first (your parent can read it to you if you wish)

Below are some questions that I should like to know the answers to. I want to give you much more time to think about them than you would have in your first meeting with me. But I don't want you to make yourself ill, so take your time and do it in short bite-size pieces. You can get your parents to help.

You don't have to do it all. But please fill in what you can manage because it helps me to plan what I will talk to you about. If there are questions you find difficult, leave them. I'll help with those when we meet.

Some questions may not be relevant to you, so just leave those.

Please send it back to me (even if not complete) by _____ before I come to see you, to give me time to read the answers you gave.

When we meet I will be able to ask more about you, and discuss your answers. Your answers will help me to advise the Local Education Authority, your school, your home tutors or other teachers with whom you come into contact. I will be able to explain exactly what you find hard and how best they can help you.

Before I arrange to meet you, it is important for me to know how your illness affects you and whether I will be meeting you at home or at school.

I will also need to know the best time of day to meet you, and how long it is likely that you will be able to talk or work with me. Assessments can take up to about 2 hours, but this can be broken up with rest breaks, or can be carried out on separate occasions. I do not want you to feel ill afterwards so please don't try to over-reach your energies.

I will contact your family/school to find out about where and when to meet with you.

Questions for you to complete

Someone can help you and you can take your time over a number of days. Wherever possible, keep answers brief to save energy. You can tell me more when we meet.

About you

Name:

Date of Birth:

How old you are now in years and months:

School year:

Key Stage:

School:

School address and telephone numbers:

Name of SENCO or person appropriate for us to contact:

Circle the name of the illness you have been diagnosed with:

Chronic Fatigue Syndrome

ME

Post Viral Fatigue Syndrome

CFS/ME

ME/CFS

Other (write the name here)

How long do you think that you have been affected?

Have any of your doctors given you any advice about education?

Would you like us to liaise with your doctor/s? (If you would like us to work with them we will need your written permission.)

We need to understand your mobility needs:

Do you use a wheelchair? (If not, tell us if you think it would help.)

If you go to school sometimes, how do you feel after the journey? (Say how you get there and back.)

How do you feel if you have to get around the building? (Say how you get around.)

Do you need to use a lift?

Anything else you'd like us to know about your mobility needs?

We need to consider your social needs as well. Do you think you might be able to manage visits to school to see friends, if you don't have to attend a lesson?

How often can you attend school (doing lessons as well as visiting the building) without feeling ill?

Do you have to take time off in order to get over it or can you maintain this pattern week after week?

What is your sleep pattern like?

Do you find some parts of the day where you feel better than others?

If you have any difficulties with the following, please write 'yes' or 'no' beside them. Don't give lots of details, but do indicate what the main problem is.

Vision/perception

Hearing

Feeling shaky and wobbly

Feeling breathless

Trembling hands or fingers

Feeling too hot or cold

Becoming distressed

Understanding what is said to you

Speaking

Feeling faint

If there are other difficulties you wish to note, list them briefly.

If you have lessons at home do these problems make it hard for you to learn? If yes, explain briefly.

Note down some ways in which these problems have made it hard for you in school.

Does using a computer make you ill?

If yes, do you think it is just because you went on for too long?

Do you have a computer at home? (PC or Mac?)

Are you online? (Dial-up or Broadband?)

What aspects of your learning were difficult for you before you were ill? Explain briefly.

Can you tell when you have done enough and need to take a break?

Is there anything your parents notice about how you look just before you feel ill? Please tell us, so that we know too. It will help for your teachers to have this information.

Friends and feelings

Are you able to be involved in any after school activities that you used to enjoy?

Are you able to see friends after school and/or weekends?

Do you have friends who come to see you or ring you up?

Do you find yourself getting irritable, moody or depressed?

If yes, has anyone tried to help you through this?

About school

At the end of each of these questions you might like to ask yourself 'what would need to change to make this manageable for me?' Then you can tell me when we meet.

Do you feel that any of your school staff understand your illness? (Do not write names.)

On the whole, is your school flexible about what you can and can't manage?

Have you heard of/do you have a Tymes Trustcard? (It is a passcard signed by your headteacher that you can show any member of staff if you need a break or other help.)

Has your school offered you a similar card?

Do you think a passcard might help?

Have you got examinations or SATs coming up?

If so, are they worrying you?

Have you got any deadlines that you have to meet for coursework?

Would you like help negotiating how much coursework you need to do?

Is there anything we haven't asked that you would like us to know about? It might be something about you, your illness or a suggestion as how we can make things easier for you?

About your doctors

Name of your GP:

Name of your Consultant(s):

Name and position of any others:

Thank you for answering all these questions. Now please tell us:

How many hours/days did it take?

Did you do it in short bursts?

How long did you spend on each occasion?

Did someone else have to help you?

Did you get symptoms (feel ill) as a result?

Do you feel you paced it about right?

This helps us to understand how much you can manage at one time.