

# *Our Needs Our Lives*



*what young people with ME  
require from a CFS/ME clinic*

*the young ME sufferers trust*

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# *our needs our lives*

*what do young people with ME and their families require from a CFS/ME clinic?*

## **The Essex Study**

The questionnaire used by The Young ME Sufferers Trust was designed in consultation with Dr Nigel Hunt, General Practitioner, Associate Director of Post Graduate GP Education, Eastern Deanery. In many cases the questions were answered by the whole family.

Ages given are as of the survey date. In many cases, these young people have been ill for years.

16 is normally a transition age for medical services. Two thirds of our respondents have reached this age, making this report relevant to adult ME clinics as well as paediatric services.

## **Focus Group**

As context for these results we asked the Trust's permanent focus group to discuss how ME clinics could help with two key issues faced by young sufferers.

## **Beyond Essex**

For comparison, we also present opinions from our members elsewhere.

*our needs our lives - tymses trust*

*this project was funded by the  
Local Network Fund for Children and Young People*



**local network fund**  
for children and young people



**ESSEX**  
COMMUNITY  
FOUNDATION

## **Please Don't**

*Please don't tell me I look just fine,  
Please don't say that I'll be right in no time  
When I can hardly make it through the day.  
You don't have to live this life  
So please don't tell me you know what it feels like  
Or how it really is to be this way.*

*Please don't tell me I'm just a little tired,  
Don't shake your head and say I'm not really trying  
When I want to spend some quiet time in bed.  
"Come on, let's get you out the house,  
We all have our ups and downs."  
You haven't heard a single word I've said.*

*Potions, pills and wonder cures –  
I don't believe in miracles.  
I only wish you understood the truth,  
That to watch and wait and pray,  
Live in hope from day to day,  
Is all that either one of us can do.*

## **Catie Jenkins**

*From Young Hearts*  
Inspirational poetry by children and young people with ME  
Foreword by Terry Waite CBE  
Published by The Young ME Sufferers Trust

## *Why is there a need for this report?*

*ME is now recognised as more disabling than many other chronic conditions*

ME is a neurological disease. It is classified as such, under the name Myalgic Encephalomyelitis and also as Chronic Fatigue Syndrome by the World Health Organisation. The UK government officially endorses these names and this classification. (ICD 10 G93.3)

It has been very disturbing and distressing for us to read, over a period of years, the many sad letters and emails we receive from children and young people with ME and their families whose needs are not being met.

The great majority report feeling disempowered and ignored. They report decisions that will profoundly affect their lives being taken out of their hands, with little understanding or consultation. They report ending up even more ill, with no suitable education or medical support.

Our Advice Line Team hears the same distressing story. All too often, families and children contacting the Advice Line report not being given choices about how they are cared for, or about the treatment they are offered.

They report that their education is rarely organised in consultation with them, so as to help them in the best possible way for their own needs.

Instead, they are presented with "done deals" that they have to either accept or fight against, thus being labelled as troublesome families with difficult children.

This leads to serious misunderstandings when doctors, teachers or social workers feel that there must be some psychologically unhealthy motivation driving families that do not accept what has been arranged for them, but who instead request something different.

When we first announced that we would be studying what young people and their parents actually need from the ME services being developed with Government money, our study was widely welcomed.

Brilliant news about the grant for investigating what we want from new services. Although I live outside the catchment area for this Report, I would also love to please complete the survey.

**Sazza Holmes**

Because of this enthusiasm, we have done our best to make this study inclusive. From the information gathered from Essex and from wider afield, we can see that what families want and need is consistent from area to area, and that in producing this report focusing on the charity's home county of Essex the Trust has also potentially helped children in the rest of the country, who will be able to use the report to explain what services they need in their areas also.

**There is huge expectation on these new clinics being set up in various areas of the country, and on those responsible for delivering the new services.**

Young patients and their families are clear about their views and expectations, and about what they do not want to see - they do not want their condition being officially "psychologised" just because there is no medical therapy that can cure the condition.

The content of *Our Needs, Our Lives* speaks for itself, but the main message coming across loud and clear is this: there is a pressing need for practical help and real understanding of the illness.

These young people are simply asking for their disabilities to be properly recognised so that their bodies can be supported while they heal.

How are we supposed to heal, when people keep making our symptoms worse? On top of that, when you ask them to be considerate, they make it quite obvious that they don't think it matters if they make you worse!

**Katie Durben**

It is our hope that this Report will be used throughout the UK to indicate the kind of services that young people need, and that it will greatly influence what is provided.

## *focus group : taking children seriously*

*children with ME just want to be believed and understood*

**We asked: In what ways could an ME clinic help children with ME to be taken seriously by their own GP, by their family, and by the community?**

This is one of the key issues frequently raised by children and young people with ME and their families. The text in this section is taken directly from their responses.

An ME Clinic should:

- "Give a positive diagnosis and be willing to write confirmatory letters"
- "Provide information on ME generally, but also include information on the severity of some cases"
- "Provide ongoing letters/reports to GPs, informing on progress and ability"
- "Help children with strategies for explaining their illness to others, both by supplying information and by taking action to help"
- "When the child is diagnosed, send a basic explanation of ME to GPs"

"Children with ME just want to be believed and understood. Maybe leaflets could be produced similar to those on other conditions, explaining the seriousness of ME, and letters could be written to GPs, parents, community, stressing that ME is a real illness and how children are affected by it. I don't think it helps for it to be called Chronic Fatigue Syndrome as people just think the children are tired. It is important not to talk about fatigue as if it were the only important symptom."

"The clinic can give invaluable support by helping people understand ME more. A trained professional can give more support by writing letters and getting in contact with a person's GP to explain the situation and help get a patient's needs across."

"Anything that supports the young person would be a good idea. Educating newly diagnosed people and their families would help them to understand how to manage."

It is very difficult to stand up for yourself when you have ME, and the younger you are, the harder this is. There should be an advocate to talk for the young person if needed.

**Katie Durben**

"Attending an ME clinic would definitely help children be taken seriously in general. At the moment, many children do not have access to an ME specialist doctor or nurse. They are just seen by doctors for individual symptoms or by a general paediatrician. After all, most illnesses do have specialist doctors/nurses, so why not ME?"

"Some sort of telephone consultation service would also be of benefit."

"The clinic should provide training days for GPs."

## Severity

"There should be no false promises. This is a serious illness and I think it should be portrayed as such. Over-optimistic approaches were very unhelpful for me. I needed to be given permission to adapt."

"The clinic should encourage energy-efficiency, such as the strategic use of assistance and equipment."

"In severe cases it should help with wheelchairs, stair-lifts, hoists and other things."

"Someone to explain to children's families that ME pain is a very unusual type of pain would be helpful. Having to spend years in the dark with ear plugs in and being so vulnerable is quite frightening, especially as it is almost impossible to get away from noise and light. Even families can be inconsiderate when they don't understand."

## Using Respectful Language

"One care plan included the sentence: 'Emma would like to reduce her reliance on her mother to meet her demands throughout the day.' This was negatively worded and also gave the impression that Emma was demanding."

"It would be more respectful to write: 'Emma would like to increase her independence from her mother in meeting her needs throughout the day.'"

"Subtle differences in wording can make a big difference."



## Boosting self-esteem

**"I was looking through some family memorabilia and came across a certificate 'for bravery' given to my brother when he broke his arm."**

"It struck me as a really good way of showing children respect and appreciation without having to spend a lot of time on it. Something as simple as this from a doctor might have helped to undo some of the deep hurt caused by doctors treating me as if I wasn't seriously ill."

## Confidentiality

**"One professional sent a letter along the lines of: 'Emma thinks this...' to everyone involved in my case, without my consent. "**

"I had thought our conversation was confidential, and in any case, this person misrepresented my views. I felt that this contributed to misunderstandings and that I should have had a say in how my own views were portrayed by someone else."

"We think that there needs to be a clear confidentiality policy."

The clinic could run groups where children and/or parents of those with ME could meet and find ways to help young people with ME to have more of a voice about their illness.

The clinic could help to highlight the terrible isolation that those with ME face when all their friends have grown tired of them and their ME and the impact this has on their self-confidence.

The clinic could help those with ME to find an effective way of managing their illness and education so that they do not continually have relapses.

More than anything I think it would be really good to have somewhere to go where you could talk to someone who understands about ME.

**Elizabeth Colley**

## *focus group : supporting education*

*ME/CFS is the biggest cause of long term sickness absence from school*

**We asked: How would you like to see an ME clinic helping children with ME with their education?**

Education is a key cause of relapse in children with ME and a serious concern in around 90% of our Advice Line calls. The text in this section is taken directly from the focus group responses.

An ME Clinic should:

- "Support the Tymes Trustcard." [see page 37]
- "Write letters confirming diagnosis and support all types of education."
- "Support examination concessions to support all the patient's needs."
- "Be open to breaks in education where necessary."
- "Have a flexible attitude to different types of learning such as home tuition, distance learning, the virtual classroom, and to different subjects that individual patients choose."
- "Be knowledgeable on - or refer to someone knowledgeable on - questions about options and alternatives for education."
- "Stress to all involved, both in medical care and education, that recovery takes time."

"I would like to see the clinic giving guidance and support in making the best choice to suit the person's individual needs. This could be through letters to support home education and/or a period of convalescence, going through all the options available and helping to maintain a good understanding of what the patient wants."

"I think it would be an excellent idea to have the clinic help with home tuition/education letters etc. So many parents have problems getting support letters for their child and some even have to pay private doctors just for a letter. This is extremely expensive, especially as some schools or tuition centres require a letter every term."

"ME Clinics could help with education by liaising with schools to explain how the illness affects youngsters. Maybe they could provide information to be passed on to the child's class and friends, but most importantly, provide support for home tuition."

"Perhaps a suitably qualified person within the clinic could have the authority to recommend home tuition."

"I think the importance of a good doctor's letter cannot be over-emphasised. The school treated me in an inappropriate way for 18 months and I believe this was primarily due to a lack of clear medical leadership. When a specialist doctor wrote a supportive letter legitimising the seriousness of my illness and explaining my needs, the school was empowered to support me. I quickly received appropriate education and my quality of life improved dramatically."

"The clinic should provide information about different learning methods, cognitive difficulties, other problems, strategies, and examination concessions. It should work with the Local Education Authority or other education organisations to get good guidelines in place and to make sure that the needs of people with ME are included in appropriate documents."

"The patient may already have a clear idea of what strategies might be helpful for them, and the doctor could help by expressing support for these ideas to the family/GP/school."

"Where the student is suffering from more than one illness, they should be given all the support they need for both conditions, even if it is expensive."

"The clinic could have someone to talk to schools, home tutors, pupils and teachers to help them understand what the reality of ME - and living with it - is. Although recovery takes time and it may take years for full-time attendance to be possible, if at all, the more compliant and sympathetic the support system is, the faster it may happen and the least traumatic and damaging it is."

"Everyone should acknowledge that just because something 'worked' - or appeared to work - for someone they know, or because someone "got better in half this time", this may be completely irrelevant to the case under discussion."

"Reducing support, taking away or denying access to physical aids such as wheelchairs, attempting to re-introduce Physical Education for the student should all be carefully checked with the ME clinic, which would provide letters and advice in such circumstances. PE should be the last thing to be re-introduced, and if it is re-introduced, this should be very gradual."

"When a student returns to school, however part-time that might be, the teachers should listen to the student to see what effect it is having on them."

**"Education should come second to health. Recovery and happiness and a listening ear should be put first. Comparisons with other students who may have ME can be a form of discrimination and should be avoided."**

## *essex : experiences to date*

*first of all, we asked our essex members about their experience of the medical profession so far*

- 37% had found medical professionals helpful with their ME
- 63% had not found medical professionals helpful with their ME

### **Negative Experiences**

"They were unbelieving, looked for mental reasons."

*Jessica Readhead, 12½*

"Our GP has been supportive but the consultant, although he gave a quick diagnosis, did nothing afterwards. As soon as our son was getting better he suggested to the school and home tutors that he was a school refuser. This led to him returning full-time. After 3 days, he had a relapse."

*Terry and Debbie Flitman*

"They refused to supply home visits or care. They thought the illness psychological and refused to investigate thoroughly even when abnormalities were found. They told me to pull myself together. They did not address my severe abdominal pain until I pushed for a referral. They were very rude and hostile and wrote referral letters talking about me having 'fixed ideas'"

*Female, 17*

"I was diagnosed by an Essex consultant paediatrician who was lovely, but GPs at three surgeries didn't believe him. I was accused of school phobia, and my parents of Munchausen's Syndrome by Proxy. I was bruised when made to sit up in hospital, treated appallingly and without regard to human rights. I saw an Essex neurologist privately and waited six months for an inpatient place but was then told I was too ill for this. My mother has filled in this form with input from me as I am unable to hold a pen."

*Catherine Huntley, 22*

"I had no help from my GP or any NHS services. My GP has always thought it was all in the mind."

*Male, 27*

"The doctor had no understanding of the magnitude of the problem. He showed lack of thoughtfulness (ie having to ask for a chair or a wheelchair) and there was duplication of tests that wasted energy. We received unhelpful and contradictory advice. He was unwilling to write to the school to keep them in the picture and 'off our backs'. There was no desire to refer to anyone else unless the family insisted, and he seemed unwilling to accept that he couldn't help."

*Parent of Child, 10*

"Many doctors have had little or no experience of patients with ME. A lot of the time, the patient educates the health professional. This is not how it should be and is not good when doctors are inflexible and unwilling to listen. This can also lead to unhelpful and dangerous practices, attitudes and treatments."

*Female, 23*

"My GP did not take my symptoms seriously at the beginning of my illness, did not refer to the right people, and has shown no interest since. I have now changed GPs. My paediatrician tried to minimise my symptoms, although he did do other tests to exclude alternatives. When it was found to be ME, he could only refer to psychological family services. He said he wasn't allowed to refer anywhere else. His attitude improved later, when he admitted that 'getting her back to school as soon as possible' hadn't been the best course and that the 'pacing' approach we adopted was helping me improve."

*Family of Olivia Horsburgh, 12*

"The GP disbelieved the consultant's diagnosis and we changed doctors in the end. The first doctor referred us to a physiotherapist who kept telling us that my son should push himself a bit more each day! He would come home from her sessions exhausted."

*Male, 16*

"The paediatricians we saw were mainly interested in trying to force our son back to school even though home tuition had proved to be far too much for him and blood tests had shown extreme abnormalities."

*Parent of Male, 15*

"The paediatrician was hugely critical of everything we were doing initially, including using a wheelchair. My daughter is continuing to recover, but not from any support from any doctors or health professionals."

*Parent of Cassandra Woodhouse, 16*

## Positive Experiences

"My paediatrician has been supportive."

*Sarah Burge, 13*

"The doctors were able to support me at school by writing official letters, enabling me to get extra time in exams."

*Marc Davies, 20*

"My GP thought I had ME but didn't know much about it. However, he was happy to refer me on when we found an ME centre online."

*Young person, 24*

"My GP was very understanding about my condition. He wrote a very helpful letter to help get home tuition. The paediatrician did every test to rule out any other medical condition."

*Colette Waitt, 16*

"Our GP has been excellent and my son's consultant paediatrician could not have been any better. They were both always there for my son and me. Sadly, my son is now too old for a paediatrician so we now only have our GP."

*Parent of Young person, 17*

"Doctors at our surgery do not appear to have much knowledge about ME but have supported our requests for referral. We found all the information out for ourselves."

*Female, 14*

## Some Experiences were mixed

"Our local doctor has helped the most. The hospital did not want to know."

*Young person, 19*

"I missed out on so much because of no diagnosis. No home tuition, no care, no clarity. I'm sure that had I had adequate support then, I'd be better now. It hurts that I missed even my education. But the GP I have now is wonderful."

## *essex : patient choice*

*we asked about co-ordination of care at present*

- **96% would like a choice of which professional co-ordinates their care**
- 4% had no opinion on which professional co-ordinates their care
- 0% said they did not want any choice in the matter

We asked the 96% who said they would like a choice to choose their preferred co-ordinator from a list.

- **52% would like their GP to co-ordinate their care**
- 31% would like a consultant to co-ordinate their care
- 0% would like a psychiatrist to co-ordinate their care
- 0% would like a psychologist to co-ordinate their care
- 4% would like a health visitor to co-ordinate their care
- 13% would like another type of professional to co-ordinate their care

Those who asked for another professional to co-ordinate their care suggested the following:

- "A specialist in ME with the help of other health professionals"
- "A neurologist / endocrinologist / immunologist or ME specialist who believes that ME is a neurological illness"<sup>1</sup>
- "None!"
- "I would only like professional help if it was useful."

The comment was made that whichever professional co-ordinates care should be well-informed about ME.

We asked whether the type of professional chosen had already been helpful and many people said yes. However, reasons were varied.

- "No, but our new GP is much more approachable and would have handled things better."
- "Nobody, except school, has been helpful."

<sup>1</sup> The World Health Organisation classifies ME and CFS together as a neurological illness ICD 10 G93.3

*we asked if travel made their illness worse*

- **42% said that travel always made their illness worse**
- 17% said that travel usually made their illness worse
- 41% said that travel sometimes made their illness worse

**In our opinion, this finding should have a major bearing on decision-making when the clinic is set up. In particular:**

- the need for patients to be given time and a suitable venue for recovery on arrival
- how far patients are asked to travel to the clinic
- the setting up of domiciliary services
- the need for a "flying doctor" team, holding surgeries in different areas

"Travelling to and attending hospital appointments always made our son worse as he had to sit up for long periods and had low blood pressure."

"A general worsening. Aches, headache and sickness are experienced for about a week following travel."

"Exertion makes pain worse and other symptoms too."

"When my daughter was worse, all journeys would make her illness worse. A long journey would still be a problem."

"Longer journeys make the illness worse, but we have amended our life to take ME into account so we don't usually have any problems."

"I have bad headaches, nausea and stomach pains as part of the ME and need to be in comfortable surroundings - resting - when this is particularly bad, so travelling is a problem sometimes."

"I have been housebound for 8 years but before that, travelling made me worse."

"It's OK in the car, but if it is early in the day, it tires me getting ready."

"Increasing exhaustion."



"I always use earphones and sometimes an eye mask. I have less energy when I get to where I'm going and realise I can't achieve what I came to do."

"Makes me emotional as I'm worn out."

"The shortest of journeys causes a relapse."

"I rely on my mum for transport. I get periods of bad insomnia and find travelling difficult due to lack of sleep and energy. It often gives me a relapse."

"Public transport completely exhausts me."

"I get stomach aches, headaches, joint pains and dizziness."

"It usually means my rest pattern is interrupted. Any outing has to be managed carefully."

"It depends on how much stress is involved in the travelling. Car is best."

"My daughter has been intolerant of light and in a dark room for 4 years. She cannot tolerate movement in front of her."

"I am one of the Trust's older members. I drive when I am well enough, but I can only manage the local shops. When I can't drive, I use my 'Shop Rider'. It would not be possible to travel, as I have no-one to chauffeur me, everyday is a struggle just to do the essential things. I live alone, with little support."

"My son was really sick for three years and we avoided travelling whenever possible."

## essex : referral

we asked if they would be interested in referral to the new ME clinic

- 38% would be interested in being referred to the ME clinic
- 4% would not be interested in being referred to the ME clinic
- 58% would possibly be interested in being referred to the ME clinic

Since 96% of respondents would, to some degree, be interested in being referred to the ME clinic, we feel this may indicate that people have a considerable expectation of being helped. It will be extremely important that they find support, compassion and full understanding of their illness among the staff at the clinic, as so eloquently expressed by our focus group.

If only new cases are referred to the clinic, it appears that a significant number of young people could be disappointed.

The 58% who are only possibly interested in referral to the clinic have reservations about what they might experience there, compared with the way they are coping at present. There are concerns about deterioration as a result of therapies that might not suit them.

We have been sent accounts of many instances where young patients have felt let down and pressurised into daily regimes that, they reported, made them actively worse, by existing clinics held by specialists in various areas of the country including Essex. These were clinics that had not been set up within the new system of Clinical Network Co-Ordinating Centres (CNCCs) and Local Multi-Disciplinary Teams (LMDTs).

**It is to be hoped that the new Essex clinic will avoid this trap of over-expectation of the rate of recovery from ME that is possible for any particular individual.**

My son has a good relationship with our GP and trusts him completely.

**Mother of Male, 17**

Our present specialist is a long way away. Our GP has no understanding of severe ME.

**Catherine Huntley, 22**

## *essex : use of the clinic*

*we asked about co-ordination of care once the clinic is set up*

- 37% would be happy if their care was co-ordinated by someone in the clinic instead of their present GP or consultant
- 21% would not be happy if their care was co-ordinated by someone in the clinic instead of their present GP or consultant
- 42% would possibly be happy if their care was co-ordinated by someone in the clinic instead of their present GP or consultant

Comments covered a range of concerns both for and against the clinic taking on or co-ordinating care, revealing their experiences to date.

"My GP is very busy. A specialist might bring added value."

"Our confidence is in the expertise of our consultant and the centre that we access through him, but a local clinic could potentially provide the same, plus contact with other local people. That would be excellent, but it has to be staffed by appropriately qualified and experienced people."

"Our present doctors have not been helpful."

"We have had a mixed experience with ME professionals. One centre was excellent, but another gave very worrying advice in which we had little confidence."

"At the moment, our GP is sympathetic, but hasn't shown interest in taking our case on. We are in limbo waiting for funding to see the consultant of our choice. We are not happy with the London hospital to which we were referred, after being with our old consultant for two and a half years."

"The only help I have received from my GP is medication but that was no help."

"It would be easier to get appointments to the clinic than with my GP."

"I would like care to be co-ordinated by professionals with knowledge of ME."

"If they understood and believed me, it would help."

"We have proved that it is far safer not to be involved with the NHS."

"It depends on the way the clinic is run. The information I've seen suggests that the clinic is to be run by a psychiatrist. If so, my daughter would refuse to attend."

## *essex : attendance*

*we investigated how services could be accessed*

- **88% said that the clinic team should hold surgeries in different areas**
- 0% said that the clinic team should not hold surgeries in different areas
- 12% said that the clinic team should possibly hold surgeries in different areas

**Since 100% of respondents wish clinics to be held in different areas, which will minimise travelling, we would hope this finding would have a major bearing on what is provided.**

Asked roughly how many miles they would be prepared to travel to the clinic, most members stated that 10 to 15 miles would be acceptable.

A smaller distance of between 1-5 miles was suggested by some, and it was clear that not being able to travel would realistically involve outreach services in order for them to access the clinic staff.

At the other extreme, 30-50 miles was also mentioned as acceptable to a few, and one parent stated that in order to get help she would take her child any distance that was necessary, even though it would make him worse to get there.

Once more, we feel that this reveals great expectations of what a clinic could offer. Since there is not a straight cure for ME, and since improvement depends on the body's own self-healing mechanisms, it is to be hoped that young patients and their families will be helped in practical ways and supported in their own lives to allow this to take place.

Our last appointment with an ME specialist was so counterproductive and left both my son and me feeling so upset and angry that we decided not to pursue medical support for the time being. However, I would very much like him to have medical help.

**Mother of male, 15**

## *essex : practical help*

we suggested a number of ways the clinic might assist

### **All our suggestions were very popular:**

- 96% Getting a formal diagnosis
- 88% Symptomatic treatment
- 88% Getting suitable education under the law (eg home tuition, virtual education, part-time attendance at school or college, modified curriculum, special arrangements for exams)
- 88% Getting physical aids (eg wheelchairs, stair lifts, hoists, travel to school or college)
- 88% Getting benefits and disabled badges (blue badges for parking)
- 83% Getting details of support organisations

### **In addition, 25% suggested additional assistance, including:**

- Details on how to hire wheelchairs here or abroad
- Information on balancing work and leisure
- Arranging communication between youngsters to combat isolation
- Referral elsewhere if necessary

We also believe that the clinic could be a useful place to hold information on local disabled facilities, for example disabled access, shopmobility and facilities offering free carer admittance. A website might be a cost-effective way to do this.

Therapies that some members suggested the clinic consider providing were relaxation, rest, medication, reiki, homeopathy, acupuncture, gentle yoga, physiotherapy, reflexology, advice on pacing, counselling, lifestyle management advice, hydrotherapy, kinesiology. Nutritional advice was also mentioned. It had particularly helped one of our families.

In the absence of a "magic pill" to cure ME, families appear willing to try alternative therapies that might alleviate their symptoms. However, some felt strongly that the clinic should not give cognitive behaviour therapy.

## *essex : need for a helpline*

- **92% wanted the clinic to provide a helpline**
- 0% did not want the clinic to provide a helpline
- 8% thought the clinic should possibly provide a helpline

There was an overwhelming majority in favour of the provision of a helpline, and a 100% vote for the clinic to at least consider providing a helpline.

## *essex : need for domiciliary visits*

- **67% wanted the clinic to provide domiciliary visits**
- 4% considered that the clinic should not provide domiciliary visits
- 25% considered that the clinic should possibly provide domiciliary visit
- 4% did not answer this question

There was great support expressed for the severely ill to receive visits in their own homes.

## *essex : support for carers*

- **79% wanted the clinic to provide support for carers**
- 0% considered that the clinic should not provide support for carers
- 17% considered that the clinic should possibly provide support for carers
- 4% did not answer this question

The fact that no-one at all felt they would be happy if the clinic did not provide support for carers reflects the great number of calls we receive to the Advice Line expressing lack of practical support for families of children with ME from all quarters.

## *essex : diurnal variation of symptoms*

we asked what time of day they would find best for appointments

- **75% would find the afternoon best for them**
- 0% specifically chose the morning as best for them
- 17% expressed no preference between morning or afternoon
- 4% specified midday
- 4% did not answer this question

Typically, young people with ME are at their best later in the day, although this does not apply exclusively.

People with ME become worse when they make an effort. If this is undertaken at a time of day when they are not at their best, this seems to make matters worse. It can contribute to relapse or exacerbate their condition over the following days, weeks, months, or in extreme cases, years.

**Since no-one chose the morning as best for them, we would hope this finding would have a major bearing on what is provided.**

Every time that our son was persuaded to do more than he felt able to, he relapsed. The paediatrician we saw said that she had "read a a lot about chronic fatigue." <sup>1</sup>

The things she had read had told her that the way to treat it was with graded exercises and psychiatry. I think this caused her to ignore all symptoms and even the results of blood tests and a heart monitor in an attempt to force our son into school and to see a psychiatrist.

It is extremely dangerous to assume that all people who have long term fatigue as one of their symptoms are all suffering from the same thing and can all be treated with graded exercises.

**Parent of male, 16**

<sup>1</sup> There is often confusion between Chronic Fatigue and Chronic Fatigue Syndrome. Chronic Fatigue is not classified as the same illness as ME/CFS, but as a mental condition. *World Health Organisation ICD 10 F14*

## *essex : psychiatrists and psychologists*

Dr Nigel Hunt assisted in developing a simple definition of a psychiatrist and a psychologist, which he felt should be available for young people and their families when completing the questionnaire.

A psychiatrist "is a qualified doctor who specialises in mental and emotional health issues and can prescribe drugs".

Our young people and their families were asked what they felt about the involvement of psychiatrists in their care.

- **92% did not consider that psychiatrists should automatically be involved in the care of children and young people with ME.**
- 4% did consider that psychiatrists should automatically be involved in the care of children and young people with ME
- 4% did not answer this question

A psychologist "is not a qualified doctor and may not prescribe drugs but can provide psychological therapies".

Our young people and their families were asked what they felt about the involvement of psychologists in their care.

- **92% did not think that psychologists should automatically be involved in the care of children and young people with ME**
- 8% thought that psychologists should automatically be involved in the care of children and young people with ME

We have not drawn conclusions from this, but we feel that patient choice is important and that the clinic should pay close attention to the preferences of its clients.

Historically, there has been prejudice about mental and psychological conditions and about seeing psychiatrists and psychologists. However, from the responses we have received, we do not feel that this is what lies behind our members' views. Rather, it appears to be their personal experience of having a physical illness for which they need recognition and practical support in the absence of a straight cure, but which medical professionals have suggested was a psychological condition.

**Although we did not ask the young people's views on any particular therapies, many expressed grave concerns about both cognitive behaviour therapy and graded exercise therapy.**



The Report of the Chief Medical Officer's Expert Group published by the Department of Health in 2002 stated that there was no universally beneficial therapy for CFS/ME and that some treatments had made patients worse. The Report also stated that differing results of such therapies may be due to different causations for people's illness, so that even though they have received the same overall diagnosis, their bodies are not able to respond similarly to these treatments. This would suggest that a tighter diagnostic procedure is desirable.

In a private communication from a consultant in charge of an ME centre reporting on the progress of his own patients, we learnt that roughly one third of people with CFS/ME undergoing graded exercise therapy seemed to find it helpful, whereas two thirds did not, and around half of these deteriorated. Doctors' medical defence unions have now issued guidance to their members to the effect that exercise therapies need prescribing with as much care as medication.

In addition to the comments received on our questionnaires, our Advice Line receives accounts of graded exercise therapy and cognitive behaviour therapy both resulting in a worsening of symptoms. Whilst this may depend partly on the therapist, many of the reports come from patients attending renowned centres of expertise. It will be very important that young people's personal experiences are listened to and believed by the staff of the ME clinic.

**We asked our young people and their families to list any circumstances in which they felt a psychiatrist could be helpful to a young person with ME. Suggested circumstances were:**

- depression
- coping with the illness in general, if the young person so wishes
- if another psychiatric illness develops, such as schizophrenia
- if it is "all too much and the young person has expressed suicidal intent"

However one mother wrote:

- "After our experience, none that I can think of, and I say this as a former Registered Mental Nurse. I know there are and must be informed and open-minded psychiatrists out there but not in our area."

"They said I was distressed because my grandparents were ill - even though I was ill a year before my grandad, and two years before my grandma."

**Answer from a young person outside Essex**

We asked our young people and their families to list any circumstances in which they felt a psychologist could be helpful to a young person with ME. Suggested circumstances were:

- where needed, discussion of problems that may arise due to having ME
- helping those who are not coping to come to terms with the situation
- advice on how to handle inappropriate comments like “pull yourself together”
- advice on how to handle people who don’t understand the illness
- coping strategies for everyday life
- help with relationships affected by ME
- if the young person feels getting the whole family together would help, because s/he feels ignored or is being denied family support due to lack of understanding or unwillingness to accept the illness

Concerns expressed included:

- “Only if they are well trained in Pacing.”
- “Our son saw one once, but this was extremely exhausting as it involved sitting up for an hour - he was too exhausted to talk!”

## *essex : self-management*

*we asked how our members were coping at the moment*

- **75% felt they were managing reasonably well at the moment**
- 25% felt they were not managing reasonably well at the moment

The point was made that even if someone knows how to manage well, they cannot do so unless they receive sufficient support.

Asked about access to a clinic regularly, most wanted to choose for themselves when they sought the clinic’s support, but a significant number wanted regular support.

- **67% would prefer to access a clinic as and when they felt it might help**
- 8% would prefer to manage their illness without any clinic input at all
- 25% would prefer to access a clinic regularly

## *essex : cause of relapse*

*what makes children and young people with ME worse?*

In ME, many things can trigger a downturn in health, or a full relapse. Our respondents were asked to circle all that applied from the following list:

- 88% circled exercise
- 71% circled school or college attendance
- 67% circled school work
- 79% circled going out
- 25% circled immunisations (some said they did not yet know)

Given the opportunity to mention anything else, the following things were listed:

- exposure to chemicals
- brain activity - watching TV, reading
- overdoing things in general
- doing too much too quickly
- lack of sleep due to the illness
- stressful situations eg awaiting diagnosis, doctors expressing disbelief
- being expected to do too much
- cold weather
- social calls or visits
- other illnesses, even mild infections eg colds
- hospital appointments
- overdoing things in general
- employment

The point was also made that catching colds and other infections is common when a young person starts attending school or college again. There are bound to be setbacks as a result of being in a vulnerable situation.

One respondent found that cold weather made them feel bad and some said that any activity at all made them worse

"Everything is like climbing Everest and just getting through the essentials is impossible on most days."

We explained that people attending the clinic may be given the opportunity to take part in trials of various management therapies.

When asked whether young people should be asked to take part in this research, or whether they should just be offered services, there was a spread of opinion.

- 58% thought young people should be asked to take part
- 29% thought young people should not be asked to take part
- 13% were unsure

Some felt that although research is important, no pressure should be applied to young people to take part.

"Very difficult, but there may be a case for it under strict control."

"If they and their parents are happy to do so."

"Would very much depend on their energy level."

"Depends on age and also past experience of the illness."

"Only because without research, nothing will be learnt about ME."

Whilst many appeared willing to consider management therapy research, almost all people with ME with whom we come in contact are very concerned that without significant investment in biomedical research (eg tissue testing), the underlying causes of the illness will not be identified, hampering diagnosis and the development of treatment.

"I would like a lot more money going towards finding a cure for this disabling illness."

**Mother of girl, 19 (outside Essex)**

## *Essex: Severity of Illness*

*fully half of our respondents had experienced severe symptoms*

- 38% of our respondents had experienced ME very severely
- 13% had experienced fairly severe symptoms

"Unable to stand, speak, hold a cup or make sense of conversation."

"I had migrainous headaches continually, with vomiting several times a day for two and a half weeks at the beginning of my illness. I also had temporary paralysis and fainting for short periods. On relapse I have been unable to support my head."

"We had to get a wheelchair, which was a shock. We took him out of education to concentrate on getting him well [...] He gradually started to improve. In his case I feel that afternoon naps played a major part in his recovery."

"My daughter couldn't walk for 7 months, sit up, talk or eat for a month."

"For months our son had to spend almost all the time lying down."

"Bedbound; very severe brain fog."

"I had a time where I just could not even get up to go to the loo and all my food had to be liquidised like baby food."

"Very severely affected since July 1998; made some improvement but collapsed in November 2002 after an ill-advised holiday and was at 0% <sup>1</sup> for 3 years. Now able to walk 5 steps at times but still noise and light intolerant."

"I've been housebound for 8 years."

"I'm still severely affected. I'm in severe pain, have cognitive difficulties and weakness, occasional paralysis, sight problems, hypoglycaemic attacks and excessive thirst. I have lots of other signs and symptoms."

"I was house-bound and virtually bed-bound for two years. I started to try to sit up for one minute a day and increased when I was able. I am still wheelchair-bound and spend 50% of my time in bed."

**Eleanor Ward, 18 (outside Essex)**

<sup>1</sup> On the Dr David Bell CFS Disability Scale, 0% is "Severe symptoms on a continuous basis; bedridden constantly; unable to care for self."

**We wanted to know whether our members had found their doctors understanding about the severity of their illness.**

- 25% found doctors understanding about the severity of their illness
- 50% did not find doctors understanding about the severity of their illness
- 25% did not express a view on this

**We asked what might have helped but was not provided.**

"An understanding doctor."

"Early diagnosis."

"More support in the early stages."

"Being given appropriate advice from the start, on Pacing."

"Being believed."

"Acceptance that she needed a wheelchair."

"A wheelchair permanently - not 3 days a week."

"A disability badge."

"A letter to say I was ill, how I was affected, what my needs were."

"Understanding that sensitivity to prescribed medication may occur."

"Nutritional support."

"Information being sent to GPs."

"Sympathy and understanding from the GP, instead of being made to feel like a hypochondriac."

"Information being sent to schools."

"A diagnosis, a letter to say that our son was unfit for school and something to control the pain."

"No insistence on regular school visits when she was still severely or moderately affected."

"Assistance in the home when there is no parent or carer to help."

"Home visits."

"Respite care or help in my home."

"Being able to take exams at home."

"Understanding that I do not have a psychological or behavioural disorder."

"The clinic could give out information about the Trust and the number you can ring."

"The new clinic should support the Tymes Trustcard." *[see page 37]*

### **Focus Group**

"An earlier diagnosis - mine took two and a half years."

"Being allowed to convalesce as an adult ie without education."

"Diagnosis earlier than four years."

"Support of any kind - we had none except a clinical psychologist who told us it was school phobia, blamed my parents' unstable marriage and sent me back to school where I was bullied and traumatised by staff and students, made to stay against my will, do PE, and sit exams while unwell."

"I had to go back to school earlier than would be advised, so ended up in bed 24/7 having to be fed and bathed by my mum at age 14."

"Help in accessing social services support."

### **Answers from families outside Essex**

## *essex : psychological attribution*

*we asked whether doctors or other professionals had suggested that their illness was psychological*

- **79% said doctors/other professionals had suggested their illness was psychological. This statistic is higher than the findings of the BBC Panorama survey of 1999.**<sup>1</sup>
- 17% said doctors/other professionals had not made this suggestion
- 4% did not answer this question

## *essex : MSBP/FII, child abuse*

*we asked whether doctors or other professionals had suggested that their illness was caused by their parents.*

- **25% said doctors/other professionals had suggested their illness was caused by their parents. This statistic is higher than the findings of the BBC Panorama survey of 1999.**
- 67% said doctors/other professionals had not made this suggestion
- 8% did not answer this question

Doctors sometimes have to make difficult decisions about whether they are seeing a case of child abuse. However, such suspicions appear to arise disproportionately in ME.

<sup>1</sup> In 1999 a survey of families whose children had ME was carried out by the BBC Panorama programme with Jane Colby, now Executive Director of The Young ME Sufferers Trust.

- 59% of families surveyed had been told by their doctors that their child's illness was psychological
- 7% had been subject to child protection proceedings

National Statistics at that time stated that just 1 in 100,000 families may be affected by Munchausen's Syndrome by Proxy (MSBP), now called Factitious Induced Illness (FII).



Worldwide, a number of families of children and young people suffering from ME have been subject to child protection proceedings. A number have had their children placed on the At Risk Register.

Some children have been admitted to psychiatric units against their will and that of their families and denied parental visits, and some have been removed from their homes and from the care of their parents.

Some of these things have happened to our members in Essex.

We have drawn no conclusions from these figures, but we had already formed a subjective impression from our Advice Line calls, emails and letters from families since 2000 that the incidence of parents suspected of child abuse when their children have ME could be increasing rather than decreasing or remaining the same.

Another possibility is that in Essex there are more such suspicions being mooted than in other areas of the country.

Also, a high proportion of our respondents were severely ill. It is possible that being severely ill with ME increases the likelihood of such suspicions arising.

"This has caused considerable distress to the whole family, especially as three weeks after my mother was operated on for breast cancer, the GP started querying whether mine was a case of Munchausen's Syndrome by Proxy."

"My teachers suggested it."

Our son's main symptom was dizziness / orthostatic intolerance and abnormal gait which he adopted because of his dizziness. We were told that as neurological examination was normal there must be a psychological element to his problems (this was from a very eminent Consultant Paediatric Neurologist).

When we finally had to give in and admit him to hospital he was too weak to swallow his own saliva and had lost 20% of his body weight. Within 24 hours of admission he developed myoclonic jerks. We were asked whether he had a negative body image (ie was he anorexic) and whether we thought he was 'putting on' the muscle jerks.

HELP! Please educate the Doctors and Nurses.

**From a family outside Essex**

## *nationwide comparison*

*we asked families in other areas to give their views*

- 80% did not believe that psychiatrists should always be involved in the care of children with ME
- 16% believed that psychiatrists should always be involved in the care of children with ME
- 4% were unsure

We asked those who felt that a psychiatrist should always be involved, how much of a role they should have.

- 83% said a small amount
- 17% said a large amount
- 0% said they should be in charge

Where new ME centres are set up:

- 93% did not believe that a psychiatrist should take the lead role
- 4% believed that a psychiatrist should take the lead role
- 3% were unsure
- 23% did not believe that a paediatrician should take the lead role
- 70% believed that a paediatrician should take the lead role
- 7% were unsure
- 36% thought GPs' views should have equal weight with those of ME centre staff
- 50% did not think that GPs' views should have equal weight with those of ME centre staff
- 14% were unsure

**Many families thought that the personal attitude and knowledge of a medical professional was of greater significance than their specialty.**

**They also thought that "incorrect illness beliefs" are a significant and widespread problem among medical professionals, rather than among patients as suggested by the medical literature.**

### From their experience:

- 10% trusted the medical establishment to care appropriately for children with ME
- 88% did not trust the medical establishment to care appropriately for children with ME
- 2% were unsure
- 18% said personal experience of doctors caring for children with ME had been positive
- 79% said personal experience of doctors caring for children with ME had been negative
- 3% said their experiences had been mixed

We asked our families to consider what services they would like to see available for children with ME. The response to our three suggestions was:

- 87% would like diagnosis in the child's own home
- 89% would like care in the child's own home
- 86% would like respite care <sup>1</sup>

Three quarters of our families suggested additional services, including educational support, home tuition, help with benefits and other entitlements, guidance on pacing, alternative therapies, counselling, occupational therapy, training for medical staff including GPs, carer support, social support, palliative care, passive physiotherapy, dietary advice, advocacy, physical aids, details of patient support organisations "like Tymes Trust".

Some families specified that they wished to avoid graded activity programmes. Some were very concerned over misunderstandings leading to incorrect diagnoses including school phobia, MSBP (FII).

The desirability of early diagnosis was also raised.

<sup>1</sup> Respite care means children being looked after but not actively treated, eg to give the carer a break.

*thank you*

We would like to thank everyone who has been involved with the production of this report.

48 young people and parents throughout Essex gave detailed descriptions of their lives and the difficulties they have faced. Some also gave telephone interviews. Five families in other areas completed the same questionnaire and told a similar story.

Our focus group gave careful consideration to the key issues of how new clinics could support the education of young people with ME, and help them to be believed and taken seriously.

111 other members completed a simpler questionnaire and supplied extra information. This has established that the experiences and the views of children and young people with ME living in Essex are consistent with other areas.

This report could not have been produced without you all.

We now have a good consultant and are seeing a more reasonable GP within the same practice. Because of letters from consultant to school and because our secondary school is less discriminating (and more believing) than our primary school, life is much better for our family.

The effect and trauma of having a child become so suddenly and severely ill, disbelieving doctors and threats of child-protection procedures, even four years down the line, will probably never go away.

Since social services are likely to be involved, much greater education of them regarding the illness is needed.

Unfortunately we live in an area where ME (only known as CFS here) is still viewed as all-in-the-mind or worse. If the child can be proven not to be school-phobic, the symptoms are assumed to be caused by some trauma he has suffered or as the result of the parents' (or more accurately, the mother's) mistreatment of him.

The best help we could have is for ME to be considered a real and serious illness, therefore education of professionals would be our main priority.

It is very important that the staff appointed in these centres, especially those in leading roles, are well motivated and with accurate beliefs about ME.

# *the young ME sufferers trust*

services and further reading

The Tymes Trust Advice Line is open from 11.00am to 1.00pm and from 5.00pm to 7.00pm Monday through Friday; telephone 01245 401080.

The Trust's Professionals Referral Service enables doctors, teachers and other professionals to consult ME experts in their own fields. See overleaf.

The Tymes Trustcard is a pass card signed by the Head Teacher or Principal of a college. It says that a student has permission to use the facilities they need, or to obtain assistance. See overleaf.

The Trust's magazine for families and professionals is free to those under 26 years of age. Subscriptions are £9.75 per annum otherwise.

**All Trust literature is available for free download at [www.tymestrust.org](http://www.tymestrust.org).**

## Further Reading

**Long Term Sickness Absence due to ME/CFS in UK Schools; an epidemiological study with medical and educational implications**

Dowsett EG, Colby J

Journal of Chronic Fatigue Syndrome May 1997 vol 3 (2)

**The Doctor's Guide to ME in Children and Young People (revised)**

Dr Alan Franklin

<http://www.tymestrust.org/tymespublications.htm>

**The GP's Good Practice Guide to Education for Children with ME**

Jane Colby, Dr Nigel Hunt

<http://www.tymestrust.org/tymespublications.htm>

**The School Child with ME**

Jane Colby

British Journal of Special Education March 1994 vol 21 no 1 pp 9-11

**Back to School?**

Jane Colby

Special Children April/May 2003

also <http://www.tymestrust.org/tymespublications.htm>

**Pushing the Boundaries in ME/CFS**

Jane Colby

Special Children March/April 2005

**Succeeding with ME - Virtual Education for Children and Young People with ME/CFS**

Report from The Young ME Sufferers Trust

<http://www.tymestrust.org/tymespublications.htm>

**Young Hearts - Inspirational Poetry by Children and Young People with ME**

Jane Colby, Editor

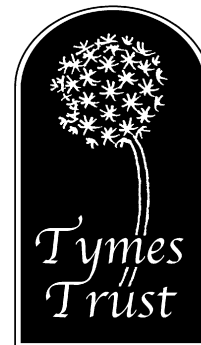
The Young ME Sufferers Trust, ISBN 0954889304

**Zoe's Win**

Jane Colby

Dome Vision, ISBN 0953733009

# *The Young ME Sufferers Trust* Professionals Referral Service



The Young ME Sufferers Trust, the longest running national organisation supporting children with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and their families, operates a Professionals Referral Service.

Faced with a case, or a suspected case, of ME/CFS, doctors, teachers, social workers and other professionals can telephone the Trust to consult an ME/CFS expert who is also a fellow professional of their own standing.

*I am pleased to assist this service. GPs can find it hard to believe that ME/CFS can mimic a brain tumour or stroke. I have dealt with extremely severe cases.*

Dr Nigel Hunt, General Practitioner  
Associate Director, Post Graduate GP Education, Eastern Deanery

The service can put professionals in touch with, among others, hospital consultants, paediatricians, educational consultants, social workers and examinations officers, all with expertise in ME/CFS.

## **Education is key cause of ME relapse in children**

The Tymes Trust Advice Line finds that educational demands are a key cause of relapse in children. Over 90% of callers report education as being the main problem or the main pressure. The Trust is often asked to run teacher training sessions for Local Education Authorities. The Trust regularly advises schools, home tutors, examinations officers and LEAs.

ME/CFS is the biggest cause of long-term sickness absence from schools. It is thought to affect 25,000 children in the UK. Tymes Trust's Executive Director, former headteacher Jane Colby, co-authored the world's biggest study of ME/CFS (*Journal of CFS, 1997*).

## **The Tymes Trustcard**

The Trust has created a Passcard system endorsed by Education Minister Baroness Ashton and the Secondary Heads Association for pupils and students with ME/CFS in school, to protect their health needs. For more information see the Trust website.

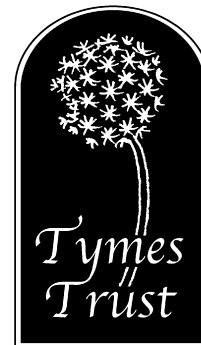
**ME/CFS is classified by the World Health Organisation as a disease of the brain and nervous system (ICD 10; G93.3). Unlike other chronic fatigue, with which it can be confused, it is a disabling, relapsing illness; minimal physical or mental effort can produce serious deterioration, typically 24-72 hours after the event.**

**Tymes Trust played a major role in the Chief Medical Officer's Working Group on CFS/ME and its Report (DOH 2002). The Trust is endorsed by the Prime Minister, the Leader of the Opposition and the Leader of the Liberal Democrats.**

# *The Young ME Sufferers Trust*

## **The Tymes Trustcard**

Endorsed by Education Minister Baroness Ashton  
and the Secondary Heads Association



*Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.*

Report of the Chief Medical Officer's Working Group on CFS/ME  
Department of Health 2002

**What is the Tymes Trustcard?** It's a "pass card" signed by your Head Teacher. It says that you have permission to use the facilities you need, or to obtain assistance.

**Why do I want one?** If you can attend school, you may meet teachers who haven't been trained in the needs of someone with ME.

Maybe you can remember needing a snack in class because you started to feel ill. This can be due to low blood sugar and it can help to eat something straight away. But eating in class is not usually allowed.

Have you ever felt that the effort of explaining would just make you feel worse? We know young people who have simply decided not to ask for what they need, or given up halfway through explaining. We know how you feel.

So, if your school has a lift but you're not allowed to use it, if you need to stay inside at break, if you haven't done homework and a teacher wants to know why, or if someone asks why you aren't in school, the Tymes Trustcard can help.

**What can it be used for?** You can quietly ask for what you need - to wear dark glasses against the light, to sit out from a lesson, to use a ground floor loo, to be excused from PE, to wear extra clothes for warmth, to eat a snack, to go to the rest room - whatever. You shouldn't need to give long explanations - just show the card to your teacher or the relevant adult. We trust you, of course, not to make inappropriate demands.

**What else comes with the card?** We send you a pack including a personal letter from us for you to give your Head Teacher so that he or she understands and can instruct staff.

**What does it look like?** The card is small and can go in your wallet or bag. It is laminated to protect it from creasing or damp.

**Does it matter what type of school or college I go to?** No.

**How do I get one?** Ring, write or email us to apply.

## **Excerpts from the Report of the Chief Medical Officer's Working Group on CFS/ME (Department of Health 2002)**

### **Treatment/Management**

- No management approach to CFS/ME has been found universally beneficial, and none can be considered a “cure”. Patient responses suggest that [...] all can cause harm if applied incorrectly.
- As with many chronic conditions, the emphasis should be on improvement and adjustment rather than “cure”. The goal of rehabilitation or re-enablement will often be adjustment to the illness.
- Experience suggests that provision of a wheelchair or other mobility aid does not stop patients working towards mobility without the equipment in the long term; indeed, such aids probably assist remobilisation, with suitable supervision.
- The notion of “once in a wheelchair, never out” is prejudicial: each case must be assessed according to clinical and functional need.
- Although there is no cure for CFS/ME, the condition has been found to improve in most patients both with and without\* treatment; it is good practice to encourage patients to become experts in self-management and to choose between treatment options. [*\* patients may therefore decline active treatment*]
- Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician.
- Careful listening and respect for parents/carers' opinions are important factors.

### **Educational Management**

- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. Some young people will be too severely affected by their illness to participate in any form of education, even at home.
- An educational plan is not an optional extra but an integral part of therapy.
- A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.
- Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.
- Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

### **Child Protection**

- In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court.
- Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.

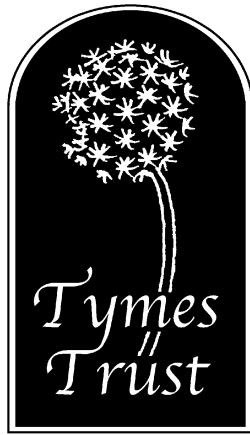
### **Prognosis**

- Overall, there is wide variation in the duration of the illness, with some people recovering in less than two years, while others remain ill after several decades.
- A minority of those with CFS/ME remain permanently severely disabled and dependent on others.
- Most people with CFS/ME can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.

**Further specialist publications for education and medical professionals are available from  
[www.tymetrust.org](http://www.tymetrust.org)**



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Registered charity 1080985*

*[www.tymestrust.org](http://www.tymestrust.org)*