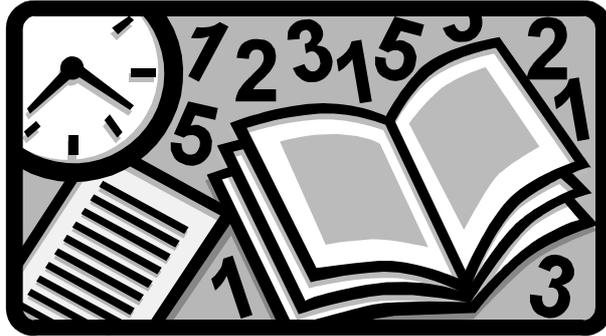


succeeding with ME

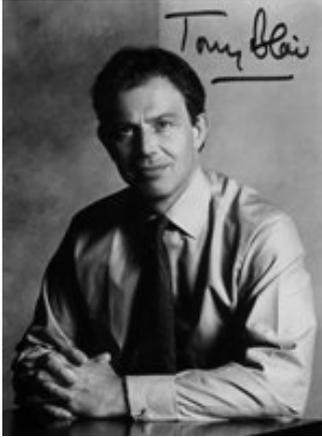


*virtual education for children
and young people with
myalgic encephalomyelitis (ME)
chronic fatigue syndrome (CFS)*

the young ME sufferers trust

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the young ME sufferers trust



The Tymes Trust is a respected national voluntary charity offering a friendly, personalised service for children and young people with ME and their families. It is committed to providing continued and expanding high quality services, whilst maintaining a long established personal approach, specialising in providing practical solutions to problems.

Prime Minister Tony Blair



I am delighted to be given the opportunity to express my personal support for the work of Tymes Trust. The range of practical and personal support that the Tymes Trust provides to children with ME is an invaluable service relied upon by families, doctors and teachers. In turn the Trust relies upon charitable donations and volunteer workers to carry out this high quality and personal service.

I wish the Tymes Trust every success in 2004.

**The Rt Hon Michael Howard QC MP
Leader of the Opposition**



Without the charitable endeavours of your organisation many young people who suffer from this condition would not get the help and support that they need. May I take this opportunity to thank all those at the Trust for the caring work that you do and wish you well in your future endeavours.

**The Rt Hon Charles Kennedy MP
Leader of the Liberal Democrats**

A handwritten signature of Charles Kennedy in black ink.

If the child doesn't fit the theory
then the theory is wrong.

**The late
Dr Alan Franklin
Consultant Paediatrician
ME/CFS specialist**

educating children with ME/CFS

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

ME/CFS 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 G.93.3)

ME/CFS is now recognised as more disabling than many other chronic conditions. Children with this condition cannot access school like their friends. Yet frequently they are bullied to return.

It is tragic that unsuitable educational demands are a key cause of relapse. Children are made more sick and achieve nothing.

Their futures are being wrecked.

But it doesn't have to be like that.

Jane Colby

Former Headteacher

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

Executive Director, The Young ME Sufferers Trust

Children with ME/CFS have been denied, and are still being denied, suitable education under the law by schools and Local Education Authorities, the length and breadth of the UK.

This does not just discriminate against these sick children's education, it affects their future chances of recovery to a level of strength and fitness that will enable them to live a normal life.

What is the government doing about this?

the forgotten children

a dossier of shame

In 2003 The Young ME Sufferers Trust published a report called *The Forgotten Children : A Dossier of Shame*.

That document was presented to Downing Street on May 12, the traditional - and international - ME Awareness Day.

The statistics from families showed that:

- 76% were not satisfied with their education provision
- 87% had had to struggle for recognition of their needs
- 81% had moved school to get recognition of their needs
- 63% had left state education
- 65% had paid for private tuition or distance learning
- 62% had felt threatened or bullied by attitudes from other children
- 84% had felt threatened or bullied by attitudes from professionals

Overall, 72% did not give a vote of confidence to State Education for children with CFS/ME.

In total, 126 families shared their experiences with us. We know of many others who were either too intimidated to speak out or just too exhausted by caring for their children every day to respond to our invitation.

Our 2003 figures are, a year later, being echoed by other studies and other heartrending stories from families around the UK.

The UK education service in many places is in crisis when it comes to educating children with ME/CFS.

an education partnership

the young ME sufferers trust has now formed an education partnership that is set to change all this

- It is ME-friendly.
- It costs less than home tutoring.
- It addresses pupils' isolation.
- It can be used when the child is well enough.
- It can be repeated in order to address concentration lapses.
- It can be used for revision.
- It enables the child to work at a suitable pace.
- It enables rest breaks.
- It can be done at any time of day.
- It is personal and individual.
- It enables each child to progress at an individual rate.

AND

- It is fun!

Surely the fact that the children already on this scheme have achieved a 96% GCSE pass rate at grades A-C speaks for itself.

Lord Clement-Jones CBE
Patron of The Young ME Sufferers Trust
Liberal Democrat Spokesman on Health in the House of Lords

The Young ME Sufferers Trust is the longest established national UK service for children and young people with ME and their families.

As a full member of the Chief Medical Officer's Working Group it played a major role in producing the children's section of the Chief Medical Officer's Working Group Report on CFS/ME (Department of Health 2002).

Nisai Education specialise in e-learning for the education sector.

Nisai has helped 20 Local Education Authorities to develop Virtual Schools and over 40 LEAs are currently using its live virtual classroom and collaboration system.

the click-on classroom

the answer for children with ME/CFS

Children with ME/CFS need contact with a teacher as much as any other child, but many are not able to attend school for long periods. The answer is to bring the teacher to them.

However, home tuition is expensive and not all tutors understand the illness. Frequently, lessons have to be cancelled when the child is not up to studying, leading to misunderstandings and accusations of truancy and even of child neglect or abuse.

What happens then?

Too many cases of children with ME/CFS turn into threatened or actual court action at the very time when a stress-free, caring atmosphere is needed, to help the child become strong again.

Children with ME/CFS also face isolation, having little contact with other youngsters. This is not their fault.

The illness does not just sap strength, it can become very severe if incorrectly managed. Some children become partially paralysed when limbs are over-used. Function returns only after considerable rest. Some of the children become unable to swallow and have to be fed by tube.

To demand too much of a child with this serious and potentially chronic neurological illness is to risk their future health.

Can the internet really help? Why does The Young ME Sufferers Trust think the virtual classroom is the way to go?

This project promises to transform the way that children who cannot go to school are taught.

**Jerome Burne
The Times**

how does it work?

*real teachers, real friends
real lessons, a real partnership*

At the House of Lords launch of the Tymes Trust/Nisai Education Partnership on 26 April 2004, Lord Clement-Jones announced:

Two years ago this month, I hosted a previous event like this, at which I was pleased to present computers from The Young ME Sufferers Trust to children with ME to help them with their education at home. I understand that this has been of great help to them.

Today we are all here to witness the start of a new partnership between The Young ME Sufferers Trust and Nisai Education. This partnership has the potential to revolutionise education for children with ME right across the country.

Around 90% of the Trust's Advice Line calls include problems with education, schools, home tutors, and other related worries. These children are very sick and they just cannot access the same type of schooling as other pupils. If they try, they become even more sick. Clearly, a radical solution is needed.

Of course, solutions do not just appear overnight. With us today are people who have been working for years to make use of modern technology in order to develop "virtual education" suitable for sick children.

Based in Warwickshire, they have been quietly setting up lesson programmes, finding suitable teachers and putting their plans into action.

And it was when they also joined forces with Nisai Education that the Virtual Classroom was born into the scheme. I'm told that this is what the children really like best. The Virtual Classroom.

What is a Virtual Classroom?

It means that children can be sitting in front of a computer at home, yet can still actually talk to the teacher and interact - just as they could if they were at school.

They have to put up their hands first of course - and to do it they click on a Virtual Hand!

The Tymes Trust/Nisai Education Partnership information explains just what the ramifications are for such a system.

The Nisai Virtual Classroom has proved very beneficial for ME sufferers, giving them access to live, remote lessons delivered by subject specialist teachers.

Previously these students would have received lessons from home tutors specialising only in one or two subjects.

The live lessons also allow students with health problems to enjoy group activities with people of their own age.

Pupils use standard computers with internet access.

The internet access can be via a normal telephone line; broadband is not necessary.

Students unable to attend scheduled classes due to ill health can access recordings of the lessons where they hear and see everything that took place during the live session.

It is also possible to pause these recordings, review parts of them, and use them for revision. The benefits to teachers are also huge.

To visit each of my pupils at home as we did before would have taken two days.

Kevin Mulryne
Teacher

What do families think?

children with ME/CFS are frequently called shirkers and truants, but most are keen to learn

The scheme addresses the restraints imposed by the illness and enables pupils with ME/CFS to prove to themselves and to others that they can achieve without their health being threatened.

ME/CFS affects

- Concentration, attention, cognition, balance, coordination and fine motor skills
- Ability to sequence words and numbers, speak, think and absorb information

ME/CFS can cause

- Exhaustion after a latent period of up to 72 hours - minimal exertion (cognitive or physical) may trigger exhaustion and relapse; the delayed effect differentiates it from other fatigue
- Generalised pain; ME/CFS can be very severe

Thank you for establishing the service. It is so necessary for children who are unable to maintain full-time education.

Grandparent of a 16-year-old boy with ME/CFS

Thank you for conceiving such an excellent system that has allowed our daughter to be included in education.

She has made significant health gains that are directly related to you and your team.

Parent of a 16-year old girl with ME/CFS

what do LEAs think?

local education authorities may subscribe for all their pupils or for just a few

Pupils with ME/CFS are not the only ones to benefit from this scheme, but they may turn out to be the largest group, since in some areas, two thirds of those on home tuition have the illness.

This places a large strain on resources and there is pressure to return the children to school or integrate them into a unit.

This can be counter-productive in ME/CFS, not just for the pupil but for society. Deterioration often sets in and the children's statutory education years pass by without their disabilities being properly and legally addressed.

The child becomes a failure through no fault of their own. This is entirely unnecessary now that we have modern technology and willing practioners.

The Tymes Trust/Nisai Education Partnership information explains the background to the scheme for pupils with ME/CFS:

Nisai Education co-founded the Nisai-Iris Partnership, a non-profit consortium of LEAs dedicated to developing and sharing online resources and best practice for the education of children unable to access mainstream education.

Nisai Education now provides a quick response service for students requiring education out of school. This service works closely with each LEA to deliver a service that will complement and extend the current educational provision. Students are tutored by teachers in other UK education authorities and attend live, online classes with students from other areas.

Warwickshire Local Education Authority were delighted when after using the Virtual Classroom for only one year 96% of these students received A to C passes in their GCSEs.

house of lords launch

from the young ME sufferers trust
executive director's launch speech

We all know why we're working so hard on this project. Because now and again, a project comes along that has the potential to change children's lives profoundly. I firmly believe that this is such a project.

ME, or Chronic Fatigue Syndrome as it's often called these days, or even ME/CFS, often arouses great passions - in doctors, in patients, in politicians, in pressure groups - and this is understandable, because where there is confusion there is often injustice.

Because there is as yet no diagnostic test for this illness, and because the criteria often used for identifying it tend to be rather wide, we mix together people who may not all have the same underlying cause for their condition, so they are bound to respond differently to treatments and also in research studies. As a result, recommendations from professionals who all have differing viewpoints and who have seen different patients frequently collide.

In short, ME/CFS is a classic example of "Everyone believes they're right - so how do we agree?" Because as we all know, ME/CFS is an area where the professionals do not generally agree with one another. Sometimes they disagree very publicly.

Where opinions collide, the child is caught in the middle. Professional recommendations are key to provision. They directly affect what kind of education we provide for children with this condition.

So let's look a little closer at ME/CFS. Is it a neurological disease? A disease of the brain and nervous system? Not only do all the symptoms point that way - the inability to think properly, the pain, the weakness and disability - and not only do the real experts in the field, those with the biggest patient databases going back decades, tell us that clinical practice demonstrates this - but research is continually coming up with findings that indicate viral damage in the brain.

Luckily the brain is pretty good at making new pathways over time, so, for example, those with ME/CFS who lose the ability to remember words and talk properly mostly regain those skills in the end. But yes, it's classified as a neurological disease by the World Health Organisation.

That is a vitally important point for the education services to recognise.

This illness is centred in the brain and no amount of pushing the child that little bit further, to attend school, to make more visits to a unit, or to complete their work or meet some other artificial target on which nature was not consulted, will make that effect go away.

Too much effort - and that can mean a very little effort - makes these children worse. Not always immediately - there is a latent period of a day or two and then the effect of effort kicks in after a slow deterioration. There are some children who manage to go on overexerting themselves for weeks or even months, trying to meet the demands of school, and they either end up crashing, or slowly going downhill until they become chronically disabled.

So we need a system of education that, whilst not costing more than it is possible to provide, keeps the children in touch with real teachers and with other children, but one that they can access without putting too much demand on their body and their brain.

When children with ME/CFS use the Virtual Classroom, you find in practice that not only are results better educationally but a number of children eventually start to become stronger.

Out of the two young people here today who have used the system, one has already been able to access school again and the other young guest is a prime example of how to come through the scheme with flying colours, despite illness.

This really is a win-win situation. We win in terms of education but we also win in terms of health.

Jane Colby
26 April 2004

in their own words ...

should we need a clear example of the need for ME-friendly education, it is surely this family's story

The amount of people I have heard say "Well ... god, I'm tired too, but you have to snap out of it and soldier on; aren't the sufferers just whingers, malingerers or perhaps mentally disturbed?"

These are questions and thoughts that I would have asked and agreed with - once. Until September 1998. Until the day my 12 year old son collapsed when he got home from school.

His face was grey, the whites of his eyes bright yellow. I can remember it all too vividly, a dull mizzling September evening. He came in, fell down; I helped him upstairs and he sank into bed, fully clothed and passed into deep, deep unconscious sleep for over 20 hours.

He had been feeling unwell since the autumn term started; we were only three weeks into it. It was his second year at the secondary school.

He has always been a bright lad, great grades all the way starting from primary school. He loved and loves to learn, soaks information up like a joyful sponge. An avid Football and Cricket player as soon as he could walk.

Anything with a ball really! The GP diagnosed Glandular Fever, said he would be unwell for a couple of months and should rest. He said he would pick up after that.

He didn't.

We were referred to a Specialist at our local Hospital in October 1998 who examined him, confirmed the GP's diagnosis, said blood tests didn't show this illness up¹, and advised antibiotics and rest. He would pick up, he said.

He didn't.

¹ Glandular Fever is diagnosable by a blood test for Epstein Barr Virus. Other viruses that cause a similar syndrome are not found by this test.

What happened next?

We went back to the specialist in November 1998 who said our son had ME/CFS. He said 40% of Glandular Fever sufferers go on to get this.

There was no cure, no medication that could help, just time and TLC. You could try alternative medicines. He had no objection.

That's it!

We booked regular monthly appointments with him to monitor our son's progress. We took him to a homeopath a couple of weeks later, in November 1998, who had been recommended to us by a well-respected physiotherapist.

He initially spent a couple of hours listening, really listening to him. He suggested we start to try and treat some of his symptoms and started with those similar to tonsillitis, and the crawling sensations which I now know to be neurological symptoms.

These remedies seemed to help him slightly with some of the symptoms and we persevered for a period of two to three years off and on. When we could afford it! One of the benefits with this homeopath was that he took the time to listen to him and treat him and his illness as an individual problem.

From experience of living 24/7 with this illness we have learnt that whilst a lot of the physical symptoms relate to a lot of sufferers, the way this manifests in each person is slightly different and needs to be handled very much individually.

There is a strong opinion that this is an illness that is basically all in the mind but this is completely wrong. Whilst outside problems such as stress or bereavement can certainly lower the sufferer more, there is absolutely no doubt that this is a real physical illness. The fact that you are treated by the vast majority as a family who basically imagines this illness does not help recovery!

It is also assumed that with ME/CFS, fatigue is the main problem. The fact that the alternative name to ME is Chronic Fatigue Syndrome (CFS) reinforces this view.

A view that is often incorrect.

Main problems can include

- Dizziness
- Tonsillitis
- Mental confusion, difficulty remembering words
- Unremitting headaches and pain, unresponsive to pain killers
- Severe shaking episodes and/or collapse
- Hypersensitivity to light, sound and smell
- Difficulty in swallowing or even in breathing
- Temperature abnormalities/sensitivity to cold and heat
- Reversal of normal sleeping/waking patterns, acute insomnia
- Crawling sensations all over the body
- Inability to walk

These are just a broad outline. He had all these!

John (not his real name) was unable to attend school

From the onset, I had duly advised the relevant parties at his school all along, firstly about his Glandular Fever and then the diagnosis of ME/CFS. I never had much feedback, to put it mildly; the weeks passed into months and John was still unable to attend much, if any school throughout that year.

The school's interest in our son's condition was almost non-existent - they had the correct information from the specialist confirming the diagnosis but weren't responsive to my cries for help in getting some more flexible schooling for him when and if he was able.

They said they could offer no help, were not legally bound to do so, not even tutoring. One teacher kindly offered to give him an hour outside school hours if that was a better time of day for him but had her knuckles severely rapped by the "powers that be" and had to withdraw the offer.

I was perfectly understanding that from their point of view it was a difficult illness to deal with and our son was often only able to work in the wee small hours of the morning as he was completely unable to sleep.

John was denied help with education

However, we were severely disappointed that they couldn't bend the rules slightly, as he was ill and not a troublemaker. I now know that the rules are not as we were told.

Obviously, my first concern was, and is, my son's health. But as parents we were concerned that he get some form of tutoring when he was able.

In the end I arranged off my own bat with his Head of Year to bring him in at certain times of the day and pick him up. He was only just managing two or three lessons a week but he wanted to try and I wanted to help him try.

During this time I was constantly quizzed about his illness and the underlying message was that he wasn't pushing himself hard enough; I was accused of deliberately keeping him at home.

When he was in school he was also quizzed as to whether I was keeping him off. This distressed him as he was ill and trying his best and couldn't understand why this question even had to be asked.

It wasn't as if they didn't have medical clarification of his illness!

In desperation to get understanding about the illness for myself and the teachers I hit the Internet and came upon a site geared to kids with ME, Young Action Online¹. God, what a relief to read about kids with the same symptoms, to know we weren't alone.

We had felt so isolated and no one we knew really took the time to talk to us and understand what we were going through as a family.

I studied their information thoroughly, researching, firing off questions, and printing out information.

I gave the school printouts of the symptoms of ME from the organisation - an organisation used by the Government - to help us all understand it better, but the interest wasn't there - they were "too busy". I told them that a highly respected representative from the Tymes Trust had offered to come and talk to them, to help them and us.

¹ Young Action Online was created by Mark Colby in 1996 and is now Tymes Trust's partner website. The Trust's own site was created in 2003.

What was the result of offering information?

- No response
- No interest
- No help

Eventually, John picked up slightly and went into school, when he was able. He missed an awful lot but was and is a determined kid and persevered.

We bought books to study at home when he was able. We went back for our monthly consultation to the specialist, who, seeing he was a bit better and going to school a little, made the mistake of signing him off. Only a few weeks later he went downhill really badly. No school at all.

We went to a different specialist at a different hospital for a fresh approach. Once again he confirmed the diagnosis but said as a family we were managing it well and that really we were the experts and should be listened to by teachers and medical profession alike.

He prescribed sleeping tablets for our son as he wasn't getting any sleep at all. Sheer exhaustion doesn't necessarily mean sleep in this illness. Our GP concurred with this view wholeheartedly and advised the school of it.

We had been endeavouring to set up a meeting with the Head Teacher and the staff to see how they could help him. By now it was the year 2000.

The school was still insisting that it wasn't up to them to help in any way regarding teaching/tutoring. They told us that "if he could manage a bit of tutoring, he could come into school".

He "wasn't pushing himself hard enough." We explained for the millionth time that the nature of ME was such that "pushing" made the illness worse not better.

John became worse by being pushed

The more the brain is exerted the less oxygen gets to the brain as opposed to a healthy person.

John could not concentrate for more than 15 minutes maximum.

Physically he could hardly walk round the house let alone get into the school.

Yet again, our explanation fell on deaf ears and we got blank looks. I offered literature, a representative from the Tymes Trust to help, as before.

Nothing.

Then at the beginning of Year 10, September 2001 (the first year of GCSE) we had an official letter from the Local Education Welfare Department advising that they would be coming to see us regarding John's absences from school.

My husband and I were pleased in some ways at this development because we thought that maybe now we could get them to help us with the attitude of his school.

We duly presented their representative with a rather thick file of copies of letters sent, most requesting responses which we never got, copies of letters from doctors and specialists confirming the diagnosis etc etc.

John had by now been ill for two and a half years and we were tired and frustrated at the lack of interest and support for our dear son.

The representative knew nothing of our son, the school had not advised her, as they should have done.

She was very surprised at the thickness of our file and also I think that we were intelligent rational educated people.

We knew by now that the school was legally bound to help with tutoring. The lack of care had been extremely demoralising to say the least and the lack of willingness to take this on board didn't help poor John.

The facts of John's case

- He was ill
- He couldn't help it
- He had a recognised physical illness
- He was legally entitled to some teaching
- The school was obliged to supply the tutor with books etc

Eventually a meeting was arranged with the then Head Teacher and relevant 'education professionals' including a psychologist to discuss his education.

Our GP kindly volunteered to support us at this meeting, as she was totally appalled at the way we were being treated as a family and had a clear idea of what we were legally entitled to from the school. We also had supporting documentation from the specialist.

- We sat around a table
- The buck was passed
- Denials flew in the air
- Responsibility was avoided

It seemed more of a political meeting rather than a group of education professionals who wanted to help an ill pupil.

When I asked about compassion a respected education professional told me that she "knew of no teacher who could afford compassion any more".

Boded well!

Eventually the school understood that because John was not well enough to attend school he was legally entitled to tutoring from home as and when he was able and they had a responsibility to supply the tutor with the relevant back up in regard to the curriculum. To cut a long, long story short a tutor was finally arranged in the January of Year 10 (2002).

A home tutor was appointed

She would work round our son's illness we were told. She understood ME we were somewhat touchily told.

Well, she tried.

She was sadly clearly more used to dealing with "problem" children, truants and so on and was clearly frustrated when I had to cancel some of John's lessons.

He was very poorly at this time. Every time I cancelled she demanded an explanation and cross-examined me on the phone:

- "What is wrong with him?"
- "He isn't trying hard enough."
- "He needs to push himself."

I explained to her almost daily about the symptoms. I typed her a note of these. She had had the GP's advice too.

I think she was insulted. It was a slur on her professionalism. She was a teacher, I was just a mother, she knew best.

She pushed at him, ignoring his grey pallor, exhaustion.

She didn't listen to his cries of being unable to concentrate, even when his head was on the table and he couldn't raise it.

I had to step in, constantly explain. I was tired, frustrated for my son. Naturally protective, as any parent would be.

I wanted to yell at her ...

- "Why can't you hear me?"
- "Why can't you take the time to understand?"

I restrained myself for my son's sake.

One day I heard her say to him, when he explained he was too exhausted to work "... well I am tired too. I think I have got ME!"

Enough was Enough!

By now the school had a different but sadly, temporary, Head. We went to see him.

He was marvellous.

He took the time in his hectic work schedule to hold meetings, deal with our problems, made sure we got what we were entitled to.

He even spoke to the tutor for us to help her understand his illness. She said she was frustrated because he couldn't always manage the lessons, had to cancel. "Anyone would think he was ill!"

She wasn't available for Year 11.

One day the Head came to our house to meet our son and talk to him. It was so unusual the care that he took, I nearly cried. (I did when he left.)

I believe that the key to his compassion - for that is what it was - is that he had had problems at school himself. The teachers had told him he wouldn't amount to anything, he was an idiot. He told me he never forgot how it felt.

Our son missed the whole of year 10 but we bought revision books for the subjects he has been able to take and basically taught himself with our help. At the time I write this, he is about to take his 5 GCSE's next week.

We, as his parents, are so proud of him. He has struggled and is still struggling with this illness.

He has chronic insomnia and needs 3 times the normal adult dose of sleeping tablets just to get a few hours sleep - fatigue in this illness does not equate to sleep.

Our son is determined, come what may to get on in life. He is probably more determined than most of his peers.

He has become mature beyond his years through dealing with an illness and the lack of help and understanding he has received.

Lack of compassion and care

I cannot begin to describe the desperation our son has suffered solely due to the lack of compassionate understanding and real care he has received from not only education professionals but also friends.

The comments he has received from so-called friends! One particular individual took the time to tell every one of his year group that our son was not ill at all but shirking and being kept at home.

This was overheard by teachers and certainly contributed to their attitude toward him, regardless of all the medical confirmation they had received over the years.

But amazingly he has managed to maintain a core of true friends and a lovely girlfriend who has listened and been his rock.

John finally won a place at college. In case his grades had not been quite what was needed, the college were promised a report based on an "overall estimation of grades he would have achieved should he not have been ill."

Health and Education must not conflict

John is still not at all well and has to pace himself but all he wants is to be a "normal teenager" - whatever highs and lows that entails. He is a strong-minded determined young man who deserves a medal at the least.

He truly knows the meaning of compassion and could teach it to his supposed elders and betters.

Schools have forgotten the human side of life. Human beings are not machines. Life is not purely about 9-5, paying the mortgage, having the same material goods as everyone else. I like nice things as much as the next person but I have come to learn and appreciate that without health, nothing else matters.

the family's voice

we should make the following things part of the curriculum

Pupils and teachers should learn how to understand about illness, bereavement and the more emotional side of life that each and every one has to go through at some point.

- Compassion for each other is vital
- We can afford it
- We should afford it to each other
- Above all we must have time for it in order to continue to bear some semblance of humanity

Remember

- If your child has ME/CFS he or she is legally entitled to help
- Don't be fobbed off
- Find out all you can about the illness
- Hold your ground
- Fight your corner
- Don't let people bully you and accuse you of neglect or Munchausens Syndrome by Proxy

This is a real, physical illness.

There are probably 25,000 children in the UK suffering from it.

You live with it. You and your child are the experts. Make people listen. Don't let them lose compassion.

Karen Stone

I tried out the Virtual Classroom myself,
to give a lecture at the Nisai Conference
via the internet.

And yes, the children are right.
It *is* fun.

When a sick child is having fun,
they're learning.

And they're not learning
"I'm a failure, I can't manage my work,
I can't get to school so I'm falling behind,"
they're learning, "I *can* do it, I *am* worth
something, I *am* a success."

Jane Colby

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.

The quarterly *Tymes Magazine* for families and professionals is free to those under 26 years of age. Subscriptions are £9.75 per annum otherwise.

Further information is available online at www.tymestrust.org

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 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

Supporting pupils with CFS/ME

Jane Colby
SENCO Update Oct 2003, Birmingham University School of Education

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

Jane Colby, Dr Nigel Hunt
A Tymes Trust publication

Does Your Child Have A Hidden Disability?

Jill Curtis
Hodder & Stoughton, ISBN 0-340-78679-5

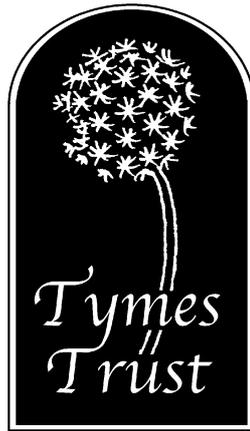
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Lynn Michell
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