

TYMES

MAGAZINE

Issue 45
Autumn 2003
£1-85



This Issue Supported by Westlands Nursery

DR LYNN MICHELL

In Conversation with
Jane Colby

EXPLORING

Is there a link between
Polio Myelitis and ME

LORD CLEMENT~ JONES

The Launch of our GP'S Good
Practice Guide to Education for
children with ME



Published by Tymes Trust
In partnership with
www.youngactiononline.com

DEREK ACORAH SENDS A FRIENDSHIP MESSAGE

WHAT'S INSIDE

Dear Reader	3
Newshounds	4
What's the Key?	6
Tymes Trust Team	8
Behind The Scenes	10
Interview: Dr Lynn Michell	12
Poetry	15
Exploring: The Polio Link	16
Why Should GPs Influence Education for Pupils with ME?	18
Seb's Manor	20
Quotes-u-like	22
Alive	23
My Special Room - The Garage!	24

TYMES TRUST

Registered Charity Number 1080985

Patron	Lord Clement-Jones CBE
Honorary President	Martin Arber
Chair of Trustees	Keith Harley
Trustees	Jennie Whitlock Sally Player Alec Western
Executive Director	Jane Colby
Design	Kerry-Ann Edge
Advice Line	Alison Ley Barbara Stentaford Gillian Stephenson Jo Mooney Margaret Howitt Meg Daffin Penny Root Toria Bicknell
Young Advisers	Victoria Western James Player
Medical Advisers	Dr Alope Agrawal Dr Alan Franklin Dr Charles Shepherd Dr Darrel Ho-Yen Dr Nigel Hunt Dr Nigel Speight
BWKT	Mark Colby

WHAT YOU THINK

We were really excited when the Chief Medical Officer's report came out last year and hoped it would make a difference but things got pretty depressing as time went on. The fact that CBT was mentioned so many times in the report seemed to blind everyone to the fact that it was not very effective.

So after a year where everything seemed to be at a standstill or even going backwards your Dossier of Shame – *The Forgotten Children* – came as a breath of fresh air and cheered us all up. You seem always to pick just the right moment to give a strong push in the right direction and I think the truth is a very powerful thing when used carefully.

Eilidh Hewitt and family

Well done for all your work on the Dossier of Shame. The shame is that it is necessary to highlight such awful things that should never be there.

Dr John Greensmith

TYMES TRUST DETAILS

Postal Address: PO Box 4347, Stock, Ingatestone, CM4 9TE

Email: jane@youngactiononline.com

Partner Website: www.youngactiononline.com

Advice Line and enquiries: 01245 40 10 80

Advice Line: Weekdays 11am-1pm & 5pm-7pm

Tymes Trust Data Protection Policy is available

Printing by Prontaprint, 11 Runwell Road Runwell Wickford Essex SS11 7PS



DEAR READER

What's the key to ME? Is there one key, or a whole bunch? One of our Focus Group writes: 'I like the magazines with a theme' and that's the theme of this edition: *What's the Key?*

When I researched my first book I was struck by the possible link to poliomyelitis. Polio was difficult to diagnose and cases were missed. In *Exploring* we show that one of the keys may be this – the two diseases are variations upon the same theme. If they *are* related, it is no wonder children with ME are frail and it is a scandal when they are disbelieved.

Laughing has a positive effect on the body. Any coping strategy should include humour, the more off-the-wall, the better!

In her research, Dr Lynn Michell uncovered lack of compassion and understanding, as we did when writing *The Forgotten Children*. This makes it vital that we hear about kind, supportive doctors and teachers. We know they are out there. Please respond to the call for your key experiences (see *Behind the Scenes*). Just a few words is enough.

Jade Scarrott (now 13) author of one of our featured poems, would like everyone to know

that she is not feeling so bad as when she wrote it, although there are still black days. Jade still writes poems. Here's another key in the bunch – express yourself, keep your spirits up through the bad times and try to find something to cheer you each day, however small.

Matthew Ecclestone of our 26+ group writes approvingly: 'Fudge is getting very big. I think that the kids' stuff in the *Tymes Mag* has much cult appeal for "older readers".' Laughing has a positive effect on the body. Any coping strategy should include humour, the more off-the-wall, the better! Another key.

We also believe it is important to represent you and to keep you abreast of resulting media coverage. This has a key influence on public opinion.

When I was asked onto the set of *Loose Lips* to meet Derek Acora, star of Living TV's *Most Haunted* and *The Antiques Ghost Show*, I didn't know he had been described as 'The David Beckham of the spiritual world!' I was touched by the warmth of his message to you (opposite).

So perhaps the greatest key to healing is love.

Jane Colby
Executive Director

IN THE SPOTLIGHT: DECREASED ABILITY TO EXERCISE

Exercise Capacity in Chronic Fatigue Syndrome Pascale De Becker; Johan Roeykens; Masha Reynders; Neil McGregor; Kenny De Meirleir. Archives of Internal Medicine; Vol 160, No. 21, Pg 3270-3277.

'When compared with healthy sedentary women, female patients with CFS show a significantly decreased exercise capacity. This could affect their physical abilities to a moderate or severe extent.'

Measuring Physical Disability in Patients with Chronic Fatigue Syndrome Using Exercise Testing Pascale De Becker; I Campine; K De Meirleir. Chest; Vol 116, Pg 4.

'Both female and male patients are limited in their capacity to perform physical activities.'

Exercise limits in the chronic fatigue syndrome Lapp CW. American Journal of Medicine Vol 103, Pg 83-84.

'The data would suggest that when PWCs [People with CFS/ME] are pushed to maximal exertion, they frequently relapse for long periods of time.'

Doctors have been advised by their medical defence unions that prescriptions for exercise must be given with as much care as those for medication.

NEWSHOUN

The publication of the Tymes Trust dossier *The Forgotten Children* continues to generate press coverage of problems we highlighted. Here are some examples.

Picture courtesy of Bucks Herald



one simple plea - *The Bucks Herald, 9 July*

When Jade Smith and her mother sent *The Forgotten Children* to the newspaper, she found herself on the front page. News Editor Andrew Worden told readers: ‘She does not want your money, your sympathy or your pity, she just wants

you to take some time to read the story of her life.’ And read it they did. Jade’s story led to two further ME features in the following two weeks.

‘Speaking from her bedroom, where the curtains are always drawn as sunlight leaves her with thumping headaches, she said the illness left her feeling “very sad”.

‘“You just want this pain to go away,” she said. [...] “I miss doing everything I used to do, like playing with my friends. Most of all I miss being able to cuddle my mum and dad.” Jade is now so sensitive to pain that she can

hardly bear to be touched. Her mother Lesley was quoted: ‘“We can’t cuddle her now and it has got to the stage where you can only kiss her on the forehead or shake her hand, it is heartbreaking. [...] Even our family cannot believe that someone like Jade could become like that, she was such a lively girl.”

‘Jane Colby, Chief Executive of the Tymes Trust which offers support to families of people with the illness, said severe ME typically developed from an initial virus – such as the one Jade suffered at nine. A lack of knowledge from doctors and teachers, she said, often made ME sufferers’ conditions deteriorate, as it is not recognised they are genuinely ill rather than just tired or depressed.’

Note: Fortunately there are kind and knowledgeable doctors and teachers, many of whom work with Tymes Trust to help others in their own professions to understand ME. If you need one of our professionals to speak to your own doctor or teacher, contact us on our Advice Line.

Sunday Times (London) 6 July

Secret courts that steal our children

Cases where parents of children with ME are incorrectly believed to be neglecting or actively harming their children are, thankfully, not the norm, but are still causing trauma and distress.

Stuart Wavell comments on the ‘high standard’ of evidence required in criminal courts, compared with family courts: ‘By contrast, family courts do not demand that a doctor’s diagnosis of child abuse should be beyond reasonable doubt, but rather on the balance of probability.’

Daily Mail 1 August

Children can sue for abuse blunders

‘Children taken from their families after being wrongly identified as victims of abuse can sue the doctors and social workers responsible’ reports Steve Doughty.

For the first time, health and social workers can be taken to court for blunders deemed to have damaged the lives of children.’ But the Court of Appeal ruled that parents cannot sue on their own behalf. This ruling was based on the ‘duty of care’ owed to a child over child abuse investigations or care proceedings, rather than to the parent.

tired and emotional* *The Observer Magazine, 17 August*

Following the publication of *The Forgotten Children*, Helen Sewell, a BBC journalist with ME herself, investigated their plight.

'Well-meaning, misinformed doctors send them back to school, sometimes with dangerous results,' she explained in a two-page article featuring Tymes Trust member Cheryl Neyt, to whom this had happened. 'Cheryl's attempted return to school was catastrophic. She collapsed, unconscious, and was rushed to hospital by emergency ambulance. Doctors discovered that her body's temperature control had malfunctioned and she had overheated. Poor temperature regulation is one of the many symptoms of ME. [...]

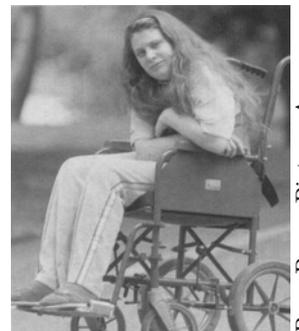
'Cheryl isn't the only youngster to suffer because of a lack of understanding by the authorities. The Royal College of Paediatrics and Child Health admits that health and education services are failing young people across Britain. Its former president, Professor Sir David Hall [...] reveals that paediatricians are often unsympathetic to children with the condition and that loving parents can be seen as over-solicitous.

'Worryingly, he says that in very extreme cases families can even be accused of prolonging a child's illness by not allowing them to take responsibility for themselves – "a type of

sophisticated child abuse". Helen details the case of Belinda White (not her real name).

'This story, though shocking, is not unique' she writes. 'The organisation Parents, Professionals and Politicians Protecting Children with Illness and/or Disability says many parents are falsely accused of abusing their ill children.' Jan Loxley-Blount, the woman behind the formation of this organisation, covered the problem for *The Church Times* (21 February). 'Dr [Nigel] Speight has already represented 14 families facing litigation,' says Helen. "In all cases justice eventually prevailed" he remarks. "But the families we hear about are only the tip of the iceberg".

Helen calculates from a survey figure quoted in our dossier (*Panorama* 1999) that 'about 1,750 of the 25,000 children with ME' could face this threat. 'Another children's charity, AYME, rejects the survey, saying it may be unrepresentative,' writes Helen. 'But as new cases continue to arise, the families involved are distraught.



Ross Parry Picture Agency

Note: If you are facing a similar problem, we recommend you act quickly to defuse the situation. Contact our Advice Line.

***Journalists do not get to choose the headlines under which their words appear.**

'I was disappointed that Helen Sewell's otherwise informed article on the injustices faced by children with ME was headlined 'Tired and emotional (OM, last week)' writes Dr Lynn Michell.

'These words contradict her sobering message and perpetuate the same old damaging image of this illness. Let's get it straight: people with ME are ill, not tired or upset. Words like these continue to do the ME community no favours.

letters - *The Observer, 24 August*

'Ms Sewell highlights a serious and widespread issue: parents unjustly suspected of "a type of sophisticated child abuse", a finding backed by Sir David Hall, Dr Nigel Speight, Tymes Trust, and by my own research. I found the experiences of families I interviewed shocking as parents reported acting as human shields between a sick child and the harmful treatments offered by the medical profession.

Dr Lynn Michell former research fellow, MRC Medical Sociology Unit, Glasgow

What's the Key?

What's helpful in *Tymes Magazine*? To guide us for the future, we asked our Focus Group. Here are some of their answers. What would you choose?

From members who like their names kept private:

Articles on pacing
Comments from members



Layout accessible re ME-brain – bite-size chunks, short quotes, highlighted text and illustrations to gladden the eye. Medical/research/treatment info explained in ME-friendly manner.

Pages quoting other members' experiences are reassuring and inspiring.

Chance for all members to participate/contribute eg birthday invitations, pictures to colour. Doing something creative for a purpose boosts self-esteem and we know you appreciate the precious energy involved.

Article on a young person's point of view about living with ME which I took to school to show teachers.

Robyn Stephenson



Advice
Different topics
Things to buy

Kirsty Watts

The whole magazine – we both love it, the articles and the education items are so interesting and helpful. It makes you feel special as though you are part of something and not alone in dealing with ME.

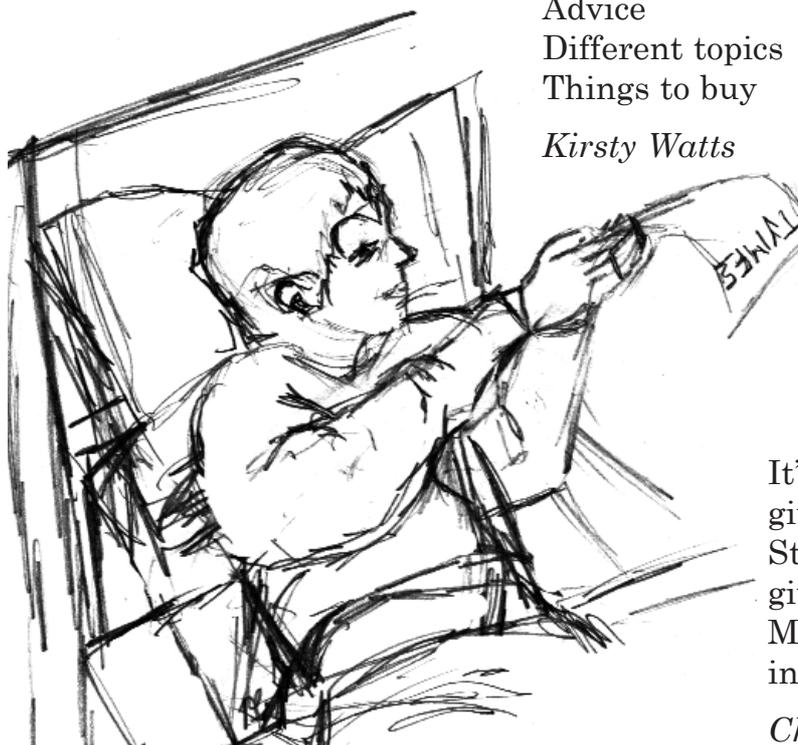
*Julie and Cheryll
Neyt*



It's nice to receive through the post as it gives you something to look forward to. Stories when someone has improved give you hope.

Medical pages with various information.

Cherie and Ryan Markham





Competitions
Interviews
Hearing about other ME children/young people

Salli and Tiffany Noble



Interviews with well known people and how they have coped with the illness.

Jessica Quilter



The competitions are always fun and rewarding. Every issue is exciting and has something of interest or of use to everyone.

It makes good, motivational reading for every age and ability. It doesn't make you feel bad for not being able to go to school/college/have home tuition. But likewise it doesn't treat those who are able to do more as any less deserving of their services.

Helpful hints and strategies of others. It's something to look forward to.

Anna Daffin

Magazine celebrity articles. Being featured in it is good for morale. Articles by ME experts who believe ME is real. Great for sanity reading!

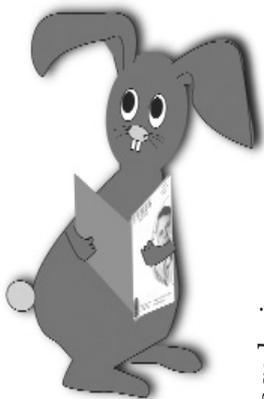
Katie Durban

Sazza Holmes

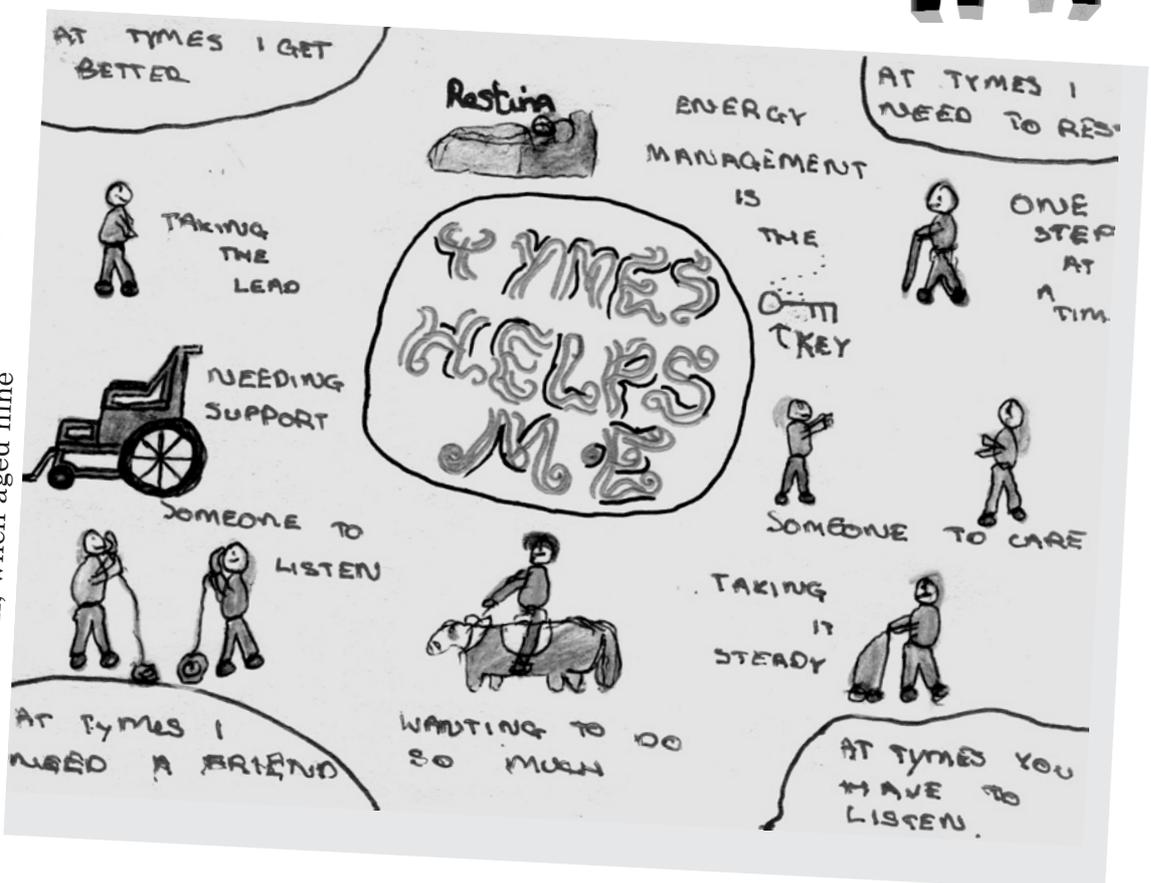
Articles from Medical Advisers.

Tez enjoys puzzles and letters from other ME sufferers.

Tez and Tell Cabrera



Victoria Western, when aged nine



Tymes Trust Team



NAME: James Player

POSITION: Young Adviser to Tymes Trust

LIVES: On the small family farm in Rettendon, a village just outside Chelmsford

AGE: 18 years

FAVOURITE COLOUR: Black (surely the favourite colour of every teenager?)

BACKGROUND: Son of Keith and Tymes Trust Treasurer and Trustee, Sally. Brother of Lucy, 15. Diagnosed with ME aged 12, during first year of secondary school. Had two years of home tuition, then attended school flexibly, studying for five GCSEs. Sat the exams at home in summer 2002, and passed with flying colours! Have just had a year out, spending time on my hobbies and interests.

HOBBIES AND INTERESTS: Taught myself electric guitar via the Internet. Enjoy practising with friends and Lucy, who is an ace drummer! Have designed a few websites, including my own music site for new British bands. Through this, have built up a network of friends across the country with similar musical tastes and get sent free promo CDs from record companies. When well enough, I go to small music gigs at local venues, and take digital photos of the bands in action. Am also mad about Arsenal FC and Grand Prix racing.

PERSONAL MESSAGE: I looking forward to adding a new Young Adviser's voice to the decision-making at Tymes Trust. ME is only a part of me and it has made me who I am. There is no point in trying to hide it from people. I just do what I can, the best I can, when I can.

Penny of the Advice Line Team writes to Head Office:

Thank you for the chocolate eggs (a very nice surprise) and for all the support and praise you give to all the Advice Line Team. Having done a similar job for another charity for years, I really appreciate your approach, as with the other one I feel somewhat semi-detached most of the time.

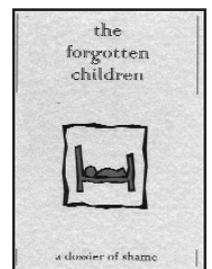
Tymes Trust certainly makes sure we never feel alone and have plenty of back-up and information. Also, the 'thank yous' are welcome!

Are you a parent or young adult with ME? Would you like to join the Advice Line Team? Contact us on 01245 401080 or write to: Advice Line Team, PO Box 4347, Stock, Ingatestone, CM4 9TE.

The Forgotten Children

Thank you to everyone who has sent in a donation to help our War on Fear since our Dossier of Shame, *The Forgotten Children*, was published. Bound copies are available at £5.50 plus 50p post and packing.

Why not give one to your MP?



Insight: Friendship

Toria Bicknell is a young adult with ME. She is also one of our Advice Line Team, during the times when she herself is well enough. A compassionate listener, here she ponders the difficulties of keeping up friendships.

Sadly, not all friendships can stand the burden of ME. Sometimes friendship is not deep enough, or as a result of illness you can change your values or ideals.

It's not always anyone's fault, so try not to lay blame. It can be painful, and no-one has an easy answer to your feeling of loss (no wise advice here).

You may find you'll choose friends more carefully and be a better friend yourself in the future.

Don't be afraid to talk this through until you feel comfortable. You'll gain a greater understanding of what friendship means and know what is most important to you.

TORIA'S TOP TIP

Quality rather than quantity.

Save your time and energy for one or two really good friends and you'll build and invest in something worthwhile. A bit like a savings account.



Toria, with her nephews in the Lake District in 2000

'Out of sight out of mind' is often true, as people with ME of all ages may discover. This can be upsetting. Remember that people who appear to have many friends often just have many acquaintances, which is not the same thing at all. Most people, no matter what their situation or health, only have a few 'best' friends.

If you would like to find someone just like you to be friends with, even at long distance, why not send in a penfriend request for us to print in the magazine? We will give you a Box Number so you don't have to give away your personal contact details.

Don't forget that you can also write to anyone who has put a penfriend request into a previous edition of *Tymes Magazine*.

Write to: Penfriend Request, Box 4347, Stock, Ingatestone, CM4 9TE.

We now have three Friends' Packs at £1.90 each including post and packing, all in protective plastic wallets.

Pack 1: Leaflets for 6 friends, showing them how to help.

Pack 2: Quick Tour of ME for 6 friends, explaining the illness.

Pack 3: Leaflets for 3 friends with 3 copies of the Quick Tour.



CHRISTMAS PRESENTS ALREADY?

Don't forget – when you buy books, CDs, DVDs, videos etc from Amazon, they will contribute to our funds. You can also buy *Shattered* by Dr Lynn Michell from Amazon.

All you have to do is click through to Amazon from www.youngactiononline.com and they will do the rest automatically. There is nothing extra to fill in and you will only pay for your purchases in the normal way.



Behind the Scenes

Trusty's choices from the latest activities of Tymes Trust

Fame

How do you feel when you are in the newspaper? Member Jade Smith reflects

Fame lasted a couple of Days
 now I am glad it's gone away
 No one knew me before
 now I am known to a lot more
 In my battle for people to Know about ME.
 I felt happiness inside of me.
 In Days to come
 Will I be remembered for my Bravery
 Or be forgotten quickly?
 In my darkened room
 I remember Days that are gone by
 a bit of courage entered my life
 hope it stays for the rest of my life.
 I thought my Fame had gone away
 but today landed on the middle page.
 Couldn't believe the reaction I had
 Some people were quite sad
 Nothing more I can say
 Just hope others like myself
 Find the courage to get through their Day.

For the newspaper feature on Jade, see Newshounds.

Readers' experiences sought

Writing the dossier made us realise how very important it is for us to know of good, kind doctors and teachers. Please send us their names and a short description of what they did to help you.

Email: jane@youngactiononline.com or post to Readers Reply, Tymes Trust

Visit to Beccles

A talk by Jane Colby. 'The ME Scandal: Tymes Trust Responds'

On a baking August afternoon, Jane and Chair of Trustees Keith Harley visited Beccles and District ME/CFS Support Group, a Tymes Trust Partner Group. Jane gave a talk identifying key points in the history of ME that have led to the present misunderstandings and showed that there has not been just one ME scandal over the years, but many. She advised members how to go about responding and helping to change things for the better.

Tymes Trust members Suzy Drake (20) and Megan Cates (14) met Jane at the meeting and Chair Brian Hindle revealed that his niece is Gill Milner, one of the two young people who started Tymes Magazine back in 1989, when no young person's ME organisation existed. Gill still receives the magazine.



This talk will be repeated, with updates, at the Norfolk ME Support Group on Saturday 27 March 2004. Tymes Trust members and their families are welcome to attend and meet Jane.



Planning ahead for your Winter Pack

We'd like to remind you that some of the inserts for your Winter pack contain references to Christmas. If your religion means that you do not celebrate Christmas, please let us know and we will amend your pack accordingly.

John Edmonds expresses his concern

Summer at Tymes Trust has meant long, hot days preparing our Autumn schedule, laying plans for the future and adding new documents to our range. We were pleased to see in-depth features in both national and local press, following up our dossier *The Forgotten Children* (see Newshounds).

Jane Colby discussed the problems at length when she met with John Edmonds, General Secretary of the GMB. John attended the May demonstration organised by CAME when we presented the dossier to No 10 Downing Street.

'It's terrible to see young lives blighted by this miserable condition,' he said. 'We must put greater pressure on the government so that more research can be funded and a proper diagnostic test developed. I send all my best wishes and the support of members of the trade union GMB.'

Trustee Sally Player regularly opens her rural garden to the public and two days a week the proceeds from the 'teas-in-the-barn' go to support Tymes Trust.

Quotes from Westlands Nursery Visitors Book

'So much effort by you to make so much relaxation for us!'

'Beautiful garden, wonderful plants to buy and scrummie cakes. We will be back!'



Note: 24 September: last day for Tymes Trust teas this year.

Find Westlands at: www.westlandsnursery.co.uk or www.ngs.org.uk

Just a line to say thank you for forwarding all my penpal replies over the last month, I've had some lovely responses. Keep up the good work

Love Rosie xxx



Saw *The Observer Magazine* article. Why wasn't Fudge mentioned?

M Ecclestone

I wanted to write and say how much I enjoyed the summer 'I Spy' Treasure Hunt. I chose to do mine using pictures of famous people because I could do it in bed without getting any help from anyone else. It was fun and I was really pleased with the result.

Claire Wade, Norfolk

BACK TO SCHOOL?

Special
CHILDREN

'Jane Colby looks at how recent DfES guidance has impacted on the largest group of pupils off school with long-term sickness - those with Chronic Fatigue Syndrome/ME' *Special Children magazine*

Many children with ME still leave state education or change school to get support and avoid unsuitable demands.

Education Minister Baroness Ashton has instructed that Jane's *Special Children* article be sent to members of the Steering Group that oversaw the government's statutory guidance *Access to Education for Children and Young People with Medical Needs*.

Jane investigated re-integration plans, home tuition, curriculum issues and rehabilitation. She reveals misunderstandings by Local Education Authorities and clarifies the government's wishes.

Re-integration plans are being put in place before pupils need them because LEAs believe the government has ordered it. This is not the case.

Pressurising sick pupils long before they are fit to return to school is *not* what the government intended.

We recommend you to read this document as a priority. Know the facts.

Back to School? Full colour 4-page A4 leaflet. From Tymes Trust, £2.80 plus 50p p&p. Courtesy of Special Children.

DR LYNN MICHELL

In conversation with Jane Colby



Lynn Michell, author of *Shattered* and a former researcher at the Medical Research Council, wants children with ME to be acknowledged and their illness taken seriously.

Jane: Lynn, you have personal experience of ME. Is that why you wrote the book?

Lynn: Partly. Having ME and having two boys with ME meant that I found many more people in the same boat, who needed to tell their stories. Particularly young people. I was finding common threads in all these stories.

I interviewed more than thirty people – seven men, seven women, seven young people, as well as their carers.

Jane: And you used the principles of qualitative research.

Lynn: Yes. I applied the methodology to the transcripts of the interviews. So I can't be accused of bias, or pulling out quotes to suit what I want to say. Strict, rigorous methodology meant that I coded every utterance. It took a year to work out a good coding scheme. Then I could count the times people said, for example, 'skiver' or 'loss' and I could look up the mention of a parent, a child, a doctor, a teacher.

That was stage one. The next stage was to translate this data, without losing the rigorous results, into a readable, accessible book. That's why it's taken me so long. It's both a research study and a book.

Jane: Did you find some parts of it distressing to write? Some of the stories are quite harrowing.

Lynn: Yes. I was most upset when I was interviewing young people and writing about them. I used to get shivers down my spine. I could hardly believe what they had gone through. You think, heavens – has this really happened to somebody of eighteen, or fifteen? Yes, I was upset.

I found it difficult to take on board the fact that these inappropriate, harsh, cruel things were happening to young people with ME today, sixteen years down the line from when I and my two sons became ill. The same stories were being told sixteen years on. So little had changed.

Jane: I'm interested in that because when Tymes Trust wrote *The Forgotten Children* we quoted from your book. It reflected exactly what we were being told. A lot of people would like to think things have changed but there doesn't seem to be a lot of change out in the field yet.

Lynn: I agree with you. I've read the dossier and I'm completely behind you on that. I found inappropriate placement and treatment for all of my seven young people. A lack of belief in what they said, inappropriate labelling – things like anorexia nervosa, school phobia, and with my own son, dyslexia – which had nothing whatsoever to do with the fact that he was so ill.

They were placed in totally inappropriate institutions. Three were placed in hospital

wards that were a disaster scenario. One was in a geriatric ward where an old woman attacked her, another was placed in a drugs and rehabilitation ward where people raided her locker. Another was in hospital for observation, only for her mother to be given a diagnosis of Munchausen's Syndrome by Proxy. So out of seven young people, three had really ghastly hospital experiences. There was a complete lack of understanding and sympathy.

When you ask me why I wrote the book, I think the primary motive was anger and a need to get this down, to document it. I know others have done it and yet we have to keep repeating that this is still going on.

Jane: Why is it that some people and even some organisations deny the evidence?

Lynn: I don't know, unless they are intimidated by the authorities or frightened to step out of line. I think it takes courage to put your head above the parapet. I wish more people in authority with a lot of status and gravitas would stand behind these young people. They're doubting still. Underneath that is the fact that there's still no diagnostic test.

Jane: What attitude would you like to see being taken by ME organisations? For example, we had to be careful with the dossier because we didn't want people to think that all doctors and teachers would treat them badly. Obviously there are some really good ones – we've worked with many of them. Neither did we want doctors and teachers to think we were just knocking them. It was a difficult exercise but we still felt it was something we had to do.

Lynn: I completely understand your dilemma. I really do, Jane, and I think you say that really well in the dossier. You're saying something that is painful to read and is possibly going to annoy or anger people in the medical and teaching professions, and yet one has to tell the truth. And you're telling the truth. I'm telling the truth. This is what's going on.

Jane: People often try to shoot the messenger if they don't like the message.

Lynn: Absolutely. From my own experience, can I say what a difference it makes when one finally finds an understanding, sympathetic GP. It's taken such a load off our minds.

When I first talked to her about my son Nye, I said, 'Do you think ME exists?' She said boldly, 'I don't think it exists, I know it exists.' The relief, Jane! It was like a great millstone coming off my neck. I didn't have to use energy

To stand up to a teacher and to admit you're different from your friends – those are two very difficult things to do.

trying to persuade her of anything. I could simply tell her what was going on and she believed me.

A good GP can make a huge difference to the quality of life of a young person. Not by curing them because there is as yet no cure, but by offering acknowledgement, believing them and listening. This GP wrote a letter saying that Nye was terribly, terribly ill and he should receive all the help and support he could get. That, for us, was like a great battle taken away.

If a carer, like me, is ill as well, it takes up so much energy fighting our child's patch. I didn't have to do that any more. A good GP can make a tremendous difference to a young person.

Jane: That is exactly our experience.

Lynn: And similarly in teaching. In the book I comment on 'the culture of blame in schools' where children with ME are blamed and called skivers – skiver was the most frequently used word in the interviews. One girl was told that when she felt a bit tired, she was to take a tea-bag and go and sit in a cupboard. She was allocated a cupboard. It's the image of the mad, bad woman being shut away from the rest of society. This is what the guidance teacher did for her. 'Take your tea-bag and go and sit in the cupboard till you feel a little bit better.'

The other image I have is a personal experience of my elder son and his friend – two of them had ME in the same year – and the PE teacher would not believe that these two boys were ill. He made the second boy run round the playing field. That boy was back in bed for three months because he hadn't got a note from home.

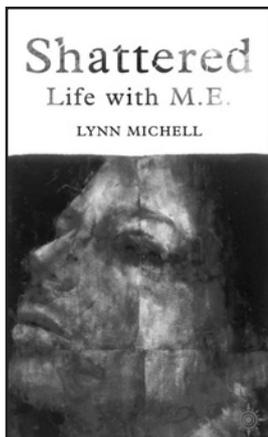
I wish we could put into action some kind of card system so that the child doesn't have to produce a sick note from the doctor, week in week out, which mine did.

Jane: That's what the Tymes Trustcard is for. It's a pass card backed by a diagnosis. Once you have a diagnosis, you can have the card. You just show it to a teacher and say 'I have permission for...' whatever you need.

The government Education Minister Baroness Ashton and the Secondary Heads Association have both endorsed it. It has the child's photograph so it can't be misused. Young people often feel they ought to do as teachers say, so the card carries the signature of the school's most senior authority – the Head Teacher. Instead of having to explain, they can quietly show their card.

Lynn: To stand up to a teacher and to admit you're different from your friends – those are two very difficult things to do. My sons would often grit their teeth and do what they were told, rather than, yet again, have somebody point the finger at them and say you're a skiver, what's the matter with you, why are you so thin, why can't you do anything? If they had a plaster cast on, they'd be treated in a more gentle way!

Jane: Quite. Eighty-one per cent of the children in our survey for the Dossier had actually changed school to get what they needed.



Lynn: And there's yet another burden for a child with ME. Having to change schools. Why should these very sick children have to be negotiating their way through the school system?

Shattered is published by Thorsons. Foreword by Vance Spence. Available from Amazon.

Jane: A teacher who attended a Tymes Trust course has won an award with her team for supporting the education of two children with ME. Would you like to see examples of good practice, with people like this involved in training teachers?

Lynn: I'd like to see a helpful attitude filtering down right through the education profession so that teachers acknowledge what the children are going through. We have to aim at universal acknowledgement of ME as a totally debilitating, devastating illness that children are managing and coping with. They're just so brave. And we should be prepared to let our children's education go by the board while they are too ill. It can be best to drop out for a while, until their bodies are strong enough to take on learning again.

Jane: And you need medical backing for that.

Lynn: Yes. A supportive doctor, a supportive teacher, a supportive tutor can change these children's lives.

Someone along the line has done a huge disservice to everybody with ME by using the word 'fatigue'. I think if we could concentrate on the complex symptoms and lose this word 'fatigue' it would make a great difference.

Jane: As someone who worked for the MRC, what would you like to see them doing?

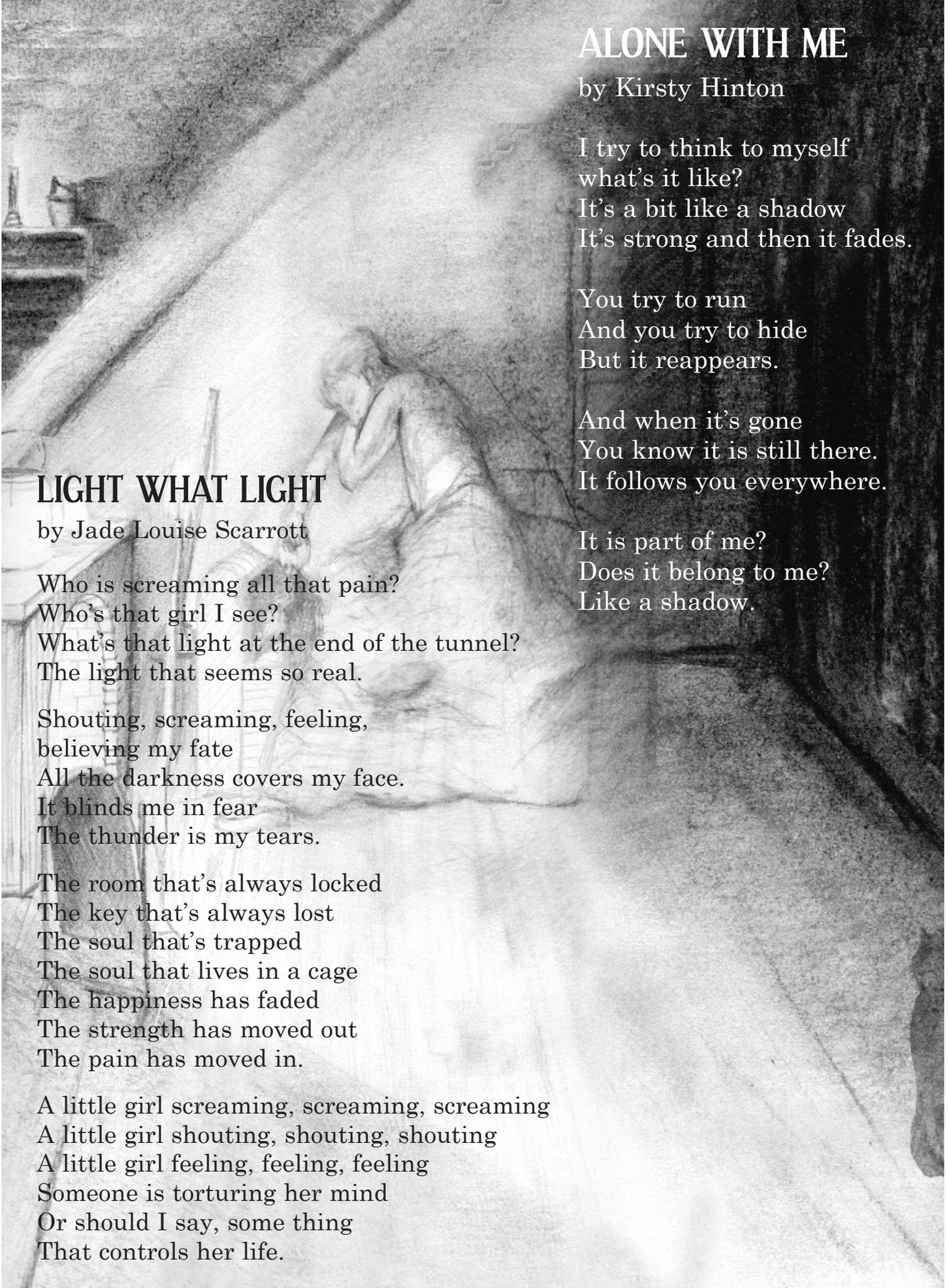
Lynn: I'd like to see the MRC and every other medical institution putting in grant applications for good medical research. Vance Spence at MERGE, despite crippling illness, is doing very good basic research into abnormalities at cell and blood level.

Too many people are researching treatments and management programmes before they've understood what's wrong.

Writing Room

Dr Lynn Michell and Helen Boden run a therapeutic and creative writing class at the alternative health and education centre in South Edinburgh. For adults (with or without problems) it offers friendship, support and a 'safe space' to talk.

*Information from:
The Salisbury Centre 0131 667 5438*



ALONE WITH ME

by Kirsty Hinton

I try to think to myself
what's it like?
It's a bit like a shadow
It's strong and then it fades.

You try to run
And you try to hide
But it reappears.

And when it's gone
You know it is still there.
It follows you everywhere.

It is part of me?
Does it belong to me?
Like a shadow.

LIGHT WHAT LIGHT

by Jade Louise Scarrott

Who is screaming all that pain?
Who's that girl I see?
What's that light at the end of the tunnel?
The light that seems so real.

Shouting, screaming, feeling,
believing my fate
All the darkness covers my face.
It blinds me in fear
The thunder is my tears.

The room that's always locked
The key that's always lost
The soul that's trapped
The soul that lives in a cage
The happiness has faded
The strength has moved out
The pain has moved in.

A little girl screaming, screaming, screaming
A little girl shouting, shouting, shouting
A little girl feeling, feeling, feeling
Someone is torturing her mind
Or should I say, some thing
That controls her life.

EXPLORING : THE POLIO LINK

Jane Colby asked Professor Richard Bruno, the American post-polio expert, to summarise the similarities with ME.

Richard: I'm not quite sure that there are any dissimilarities. The symptoms are the same.

Jane: You pointed out recently that 50 years ago, post-mortems on polio victims found the consistent presence of poliovirus lesions in the brain stem and this fitted with descriptions of their clinical symptoms.

People with ME have similar symptoms. SPECT and MRI scans [brain scans not available 50 years ago] show that the same brain areas are affected. Incomplete fragments of viruses related to polio have been identified in the tissues of people with ME and polio survivors.

Richard: Yes.

Jane: Do you feel this evidence stacks up enough to say that ME is basically a polio-related condition?

Richard: There may very well be an enterovirus relationship. Polioviruses are only three out of 72 enteroviruses [gut viruses].*

Something has got to be damaging the brain. If the polio virus does all these things to the brain and we're finding the same sorts of things in ME as in the polio people, with the lesions on MRI scans, the endocrine changes and the failure of attention and concentration, plus all the subjective symptoms: if it quacks like a duck and it walks like a duck...what else could it be? It's not possession by demonic forces.

There's got to be something underlying both conditions. And if all of these psychological and neuropsychological and clinical and physiological and endocrinological symptoms are the same...?

** Vaccination against polioviruses 1-3 does not confer protection against the other viruses in the same family.*

Are ME and Poliomyelitis related?

We explore the link.

The link between ME and poliomyelitis has been argued over for years. Polio, once very widespread, could be as difficult to diagnose as ME is today. Microbiologist Dr Elizabeth Dowsett tells the story of a little girl who was smacked for 'refusing' to put her arms into her vest. She couldn't, because the poliovirus had paralysed her arm muscles.

Mild cases could go completely unrecognised. Whole families with one severe case were often affected to a lesser degree themselves. Clusters of polio in families were common, just like family clusters of ME.

These milder cases might be missed as everyone concentrated on the child whose legs were paralysed or the child who could no longer breathe. They lay inside a machine called an 'iron lung' that did their breathing for them. Sadly, some children didn't make it. And that was the reason they were taken seriously. No-one can argue with death, or label it a psychological problem.

If ME is related, why do we do not see children with ME having to lie in iron lungs? In fact, some severe cases do experience breathing difficulties, and/or long periods when their muscles just will not work, no matter how hard they try. The message doesn't get through from the brain and, as Dr Alan Franklin reports, children say things like 'My muscles won't do what I tell them.'

One older nurse who, after retiring, came across a case of ME said: 'Why, it's just like a case of polio.'

ME is now hidden under the umbrella of 'Chronic Fatigue Syndrome' (CFS) a term now widely accepted as also covering other fatiguing conditions. The 2001 Report of the government Chief Medical Officer's Working Group talks of 'CFS/ME', but most doctors and researchers use CFS on its own.

Chronic Fatigue Syndrome is a term invented in the 1980s for research purposes. Its use for clinical purposes is seen by many, including Tymes Trust, as significantly setting back the understanding of ME as a discrete condition.

In days gone by, doctors would search for an organism or organisms that were causing each case of this illness. It was widely recognised as a polio-type illness, often starting, like polio, with what seemed to be flu. The 'flu' cleared up, but was then followed by full-blown polio-like effects.

The term 'atypical polio' was in use well before the name ME was invented. We weren't at that time constantly looking for psychological causes, except perhaps in milder cases that went unrecognised – like the milder cases of polio.

Many injustices have flowed from the scientific muddle and misunderstanding that almost certainly dates from two psychiatrists who looked at some old sickness records of the nurses at the Royal Free Hospital, London, where there was an outbreak.

In her 1997 paper *Is ME/CFS caused by a persistent enterovirus infection?* Dr Dowsett writes:

In 1955, when the study of virus infections was moderately advanced, the infamous psychiatric partnership of McEvedy and Beard declared the Royal Free Hospital outbreak of ME/CFS, affecting 292 members of staff, to be evidence of mass hysteria, despite the fact that they were writing in 1970 and had never seen a single patient so affected. One member of this partnership later went on to describe an epidemic of Winter Vomiting Disease [now known to be caused by the Norwalk virus] in a different institution as a further example of this phenomenon.

In spite of this psychiatrist's error in incorrectly labelling Winter Vomiting Disease – now famous for causing outbreaks on cruise ships – as mass hysteria, the myth of ME as a psychiatric disease, once born, has persisted ever since.

Children with polio who were sent back to school too soon suffered twice the rate of paralysis as others. In fighting for children with ME to receive proper support and education, at home when needed, we are fighting against a repeat of history.

A severe case of ME with similarities to poliomyelitis

I carried on dragging myself into work, not knowing what to do, leaving my daughter at home. Eventually I stopped work, which proved a blessing. Unknown to me, she was scarcely able to walk, but was crawling around on hands and knees.

She started having spasms – her limbs would flail about independently. She'd fall off the sofa. She forgot how to count. She muddled her words. It was like watching a computer short circuit. Very scary.

Our new, supportive GP had never seen anything like it. She referred us for tests. The hospital kept us overnight, which just made her worse. I was treated like an over-protective mother. A psychiatrist suggested family therapy. We felt humiliated and I discharged my daughter from hospital.

She was referred to a Chronic Fatigue Syndrome unit – one of the foremost in the country. They never once met my daughter; she was too ill to come, yet they still insisted on how to treat her. We tried Cognitive Behaviour Therapy, briefly, but found it unhelpful, impersonal and rigid.

Then she started having fits and was admitted for an EEG. Tests shows she was not epileptic but she was so obviously better at home. Armed with documentation from Tymes Trust, we explained to our GP what support we needed from her.

Through resting and sleeping when she needed (often strange times) she slowly improved. The GP helped with pain relief. We had a stairlift installed. We got home tutoring. Things have improved so much! We are pacing life at her own pace and not allowing anyone to persuade us into anything that seems inappropriate.

Now she no longer needs the wheelchair. This is a long way from the child who was at times unable to move at all, even breathing and swallowing being a real problem on occasion. Our child, who could not stand and support her own weight or walk for nine months, who lost the ability to count in sequence to 3, is now a year ahead of her peers with her maths GCSE.

Pip Mayo Tymes Magazine Issue 39

WHY SHOULD GPs INFLUENCE EDUCATION FOR PUPILS WITH ME?

The GPs Good Practice Guide to Education for Children with ME explains.

ME is the biggest cause of long term sickness absence from school (Dowsett/Colby *Journal of Chronic Fatigue Syndrome* 1997). This is because the typical child with ME is fragile and attendance at school aggravates the condition. GPs can have a positive influence on the educational demands made on the child so that progress towards recovery is enhanced rather than set back.

Lowered blood flow to certain areas of the brain on effort, coupled with lowered cortisol levels in the brain (both of which are noted in this condition) make it impossible for the child to cope with normal levels of effort and stress without suffering a downturn in their medical condition.

A typical bout of ME lasts around four and a half years. Many last much longer; some are fortunately shorter, but relapse is also a consistent feature in this condition. Because there is no curative therapy, self-management is the safest and most effective way of enabling the body to recover as far as is possible.

Both physical and intellectual effort produce a delayed deterioration and patients need to learn to modify their output accordingly.

Since a child has to be educated by law, the methods of education used should be commensurate with recovery. Like all medical conditions, each case will need slightly different management based on sound principles.

How do educational demands affect recovery?

Advice Line Records from support organisations and the clinical experience of paediatricians both tell the same story. They indicate that education is a key source of relapse in pupils and students. In many cases it is the main source.

Unsuitable educational demands therefore:

- a) undermine the doctor's medical management and
- b) deprive pupils and students of their legal right to education suitable for their medical and special educational needs.

Attending school is often too demanding physically, even part-time in many cases. It drains what little strength the pupil has and exacerbates central nervous system dysfunction. This produces extreme malaise, and in some cases collapse.

The very purpose of being in school, which is to learn, is undermined because the brain cannot retain information. Attention and cognition are worst affected.

Not only does this result in repeated relapse, but there is also little educational achievement to show for all this effort. Children often come to believe that they are failures. In fact, it is the system of education used that has failed. It has failed them medically as well as educationally.

What can the GP do?

Teachers may not prescribe medication, yet doctors are permitted – even expected – to write virtual prescriptions for education.

- * If a child is thought to need home tuition, distance learning, or needs to be excused from physical education lessons for a considerable period, the school will require medical confirmation of this requirement.
- * The GP is the doctor who is most accessible to the family and will often find him or herself in the position of having to make decisions on education.
- * The purpose of this Guide is to assist GPs in making those decisions. Whilst each case is unique, certain principles underlie these decisions.
- * Energy Efficient Education assists recovery and recommendations can be made that are commensurate with pacing life carefully.

Lord Clement-Jones CBE

Liberal Democrat Spokesman for Health in the House of Lords

As Patron of Tymes Trust, I am delighted to launch and to recommend the *GP's Good Practice Guide to Education for Children with ME*.

GPs are in a key position to have a major influence on both the quality of life and the educational achievements of young people suffering from this condition. The Trust recently drew attention to their plight through the publication of the dossier 'The Forgotten Children' and its presentation to the government. The dossier revealed widespread deficiencies in the way the system affects children with ME.

As part of the Trust's aim of finding practical solutions to problems, the Tymes Trustcard was launched in 2002 for use in schools. This has been endorsed by Education Minister Baroness Ashton and by the Secondary Heads Association.

The launch of this new Guide for GPs takes us further along the road towards increasing understanding and support from the medical profession.



What's in the GP's Guide?

The GP's Guide includes the information printed on these pages, plus advice for your GP on all of the following:

- * Place of Learning – choices and recommendations
- * Curriculum and Coursework
- * Examinations
- * Spectrum of severity of the Illness

Together with:

- * GP's Quick Reference Action Plan
A 6-point plan to help your GP manage your case

And information for your GP about:

- * The Tymes Trustcard – a pass card for children with ME at school
Endorsed by Education Minister Baroness Ashton and the Secondary Heads Association
- * Key Quotes from the CMO's Working Group Report
Including the paragraphs on education and child protection
- * Tymes Trust Services
- * Case History – successful collaborative care management

How do I obtain my copy of the GP's Guide?

The first draft of this Guide was developed from work on collaborative care and presented to the Chelmsford Primary Care Trust Interactive Forum for GPs and other professionals in May 2003, run by Dr Nigel Hunt and Jane Colby.

After consultation, the Trust produced the final document, which is now available for you to buy for your GP. If you have a copy of the original consultative draft, please now discard this.

For each Guide that you require, please send £4.50 plus 50p post and packing to Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE or order by credit card on 01245 401080.

SEB'S MANOR



by Sebastian the website spider (find him at www.actiononline.com)

Sebastian says:

I just found out that Matthew Ecclestone (a subscriber to our 26+ group who is often stuck in bed) has sent an email to us with a message for Fudge at the end!

Goodbye, and give my regards to Fudge.
Matthew.

I naturally sulked a bit after that—till suddenly I got a message from Matthew too!

A big message for Seb.
RESPECT!!
Matthew

RESPECT to you too, Matthew.

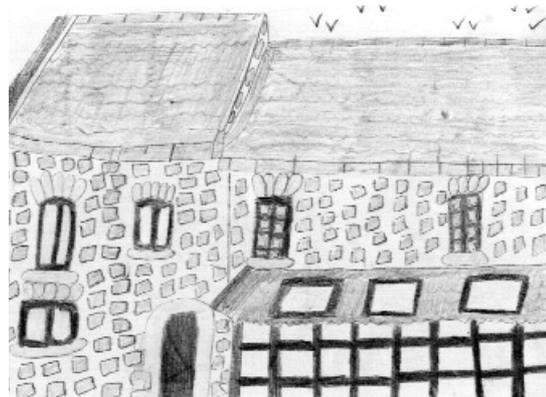
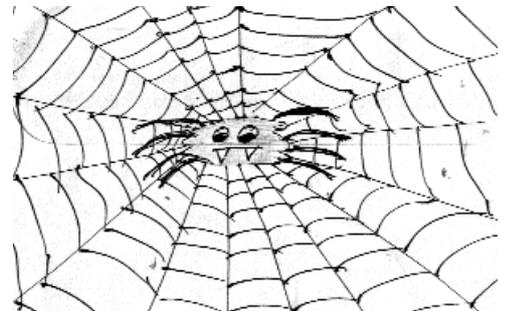
Fudge the Beanie Bear is Caramel Bear's cousin (not another one!). Our Chair of Trustees found them last Christmas. What will he find next?

HOW DO THEY FIND US?

Mark Colby sometimes gives us a breakdown of the things people type into Google or other search engines to find us on the Internet. His favourite at the moment is:

VICTOR MILDEW!

Here I am drawn by Jane Fawcett. Can you do a portrait of me too?



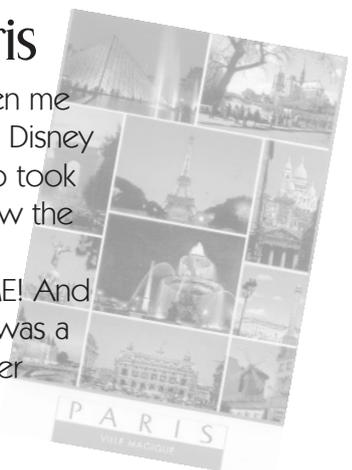
Picture by Sarah Wilcox when she was 17.

This sketch of Sarah's Yorkshire home reminds us of holidays spent in the country.

Fudge goes to Paris

Bonjour to all. Cheryll has taken me to visit Disneyland (I saw Walt Disney and Mickey Mouse!). She also took me to The Louvre, where I saw the Mona Lisa. She did look a bit miserable...maybe she has ME! And I went to the Sacre Coeur. It was a very good job Cheryll took her wheelchair.

Au revoir
Fudge (and Cheryll) X



SEB'S AUTUMN COMP

Spot the 9 differences between these two pictures.

Comp designed by Margaret Ross, one of the Tymes Trust Team. There's no time limit on this one. You can enter whenever you like. List the differences and send them to Margaret (address below). Good Luck!



Thank you very much for my Beanie. It really cheered me up as I have been in and out of hospital since April. I have named her Caramel Beau, she sits on my bed and has become great friends with Poppy the Lamb. They sit with me and watch my goldfish. Poppy is pleased because she now has some company whilst I am asleep (that's always!).



Thanks again love
Emma Gray xx
(a mum who wrote
the letter)
- X

Send letters, drawings, photos
and competition entries to:
Seb's Manor, Tymes Trust,
PO Box 4347, Stock,
Ingatstone, CM4 9TE

Quotes-u-like

'How beautiful it is to do nothing and then to rest afterward.' *Spanish proverb*

'Don't worry 'bout a thing, 'cause every little things going to be all right!' *Bob Marley*

From Jane Fawcett

Standing before the mirror that shows the deepest desires of our hearts, Professor Dumbledore tells Harry Potter:

'It does not do to dwell on dreams, Harry, and forget to live.' (*Harry Potter and the Philosopher's Stone*)

Ann Lewis sent us her moving story. She has plenty of dreams but hasn't forgotten to live as well as dream.

I have many dreams. Some are completely unrealistic but there are so many things I'd like to do. I wanted to be the youngest person to climb K2 (the mountain). I am too old for that but I would still like to go. I'd also like to see a glacier. One with deep bottomless crevasses – big enough to fit whole houses in. I love snow, ice, mountains and anything natural. I think if I could design anything in the world I would never be able to come up with anything as wonderful as the natural landscape.

I had other dreams like being clever and getting a degree but they aren't dreams any more; it's taken me 5 years of really hard work but I now have one. I did my last year via Open University and did most of the work from my bed.

I now need a job – one that pays well but only requires me working a few hours a week, but then don't we all want a job like that?

As Dumbledore wisely says: 'It is not our abilities that show what we truly are, it is our choices.' (*Harry Potter and the Chamber of Secrets*)

Why not watch the films if you aren't well enough to read JK Rowling's books?

'There are some roads in life that we must travel alone, but just remember – everyone who loves you is walking with you in spirit.'
L Wymer

From Rosie Shorter

PENFRIEND REQUEST

Hi, I'm Emily. I'm 15 this year and live near Great Yarmouth. I've had ME since early 2000. I like music (pop, R&B, dance) movies (action, comedy) the web, computers and games like Tomb Raider. I play the piano, read and watch TV shows. My dog is called Mitzi. I would like a penpal around my age, male or female, same interests and maybe lives near me? Write to Emily at Box No 037

I'm 20 and enjoy history, music (Doves, Blur, Pulp and others) and listening to the radio. I love hearing a good discussion. I was very active before I became ill and I still, even after seven years, find it onerous to handle ME. This hasn't been helped by experiencing ignorance and antagonism, which, sadly, I know isn't unusual. I don't think of myself as 'ME sufferer Chris' but a well rounded young man with good and bad points and interests, who happens to have an illness. If you feel similarly and would like a penfriend for who he is, and who'll share this approach with you, please contact me. (By the way, I'm hardly ever this serious! Honest, I do have a lighter side, but I mean every word.)

Write to Chris at Box No 038



We agree Laura - sick elves also need flowers.

Drawn by Laura Shave

ALIVE

Nye, by Dr Lynn Michell

Nye, my son, was always unwell, or so it seems. At six, you can't explain how awful you feel.

At seven he spent three weeks in an observation ward. The consultant concluded he was dyslexic (based on his drawings of 'Tebby') but otherwise physically healthy. We parents had to stand between him and the medical profession, rejecting diagnoses of anorexia, school phobia, and refusing psychiatric intervention. Our son was ill, yet amazingly sane despite his suffering.

After years off school, he relapsed due to exams and was bed-bound for four years. He weighed seven stone, was in constant pain, and suffered all the other horrible symptoms I don't need to tell you about. That was the worst time.

Improvements have come step by tiny step. Slowly, Nye adapted and lived in a way that did not stress or overstretch him, even if that meant doing very little. Progress came when he took control, but he could not take control until he had enough energy to do so.

Two years ago he took a leap for independence and moved out. He managed (sometimes only just) and his self-esteem grew. First he risked an evening photography course (requesting a stool and leaving early when needed) and then FE College. A supportive tutor often let him work from the dark-room in his flat. After five years of isolation he had friends. He submitted his portfolio in March, was accepted at Art College and starts his degree in October.

Nye is still ill. He sleeps like a dormouse, gets infections, turns green when tired, and needs lots of time alone. Living within energy limits is a daily mantra. But photography is an inspired choice because it is legitimate to spend hours quietly in a dark-room.

He has also been travelling with his mates. Sometimes he pays with days in bed, but to do too much is one of many choices he can now make for himself.

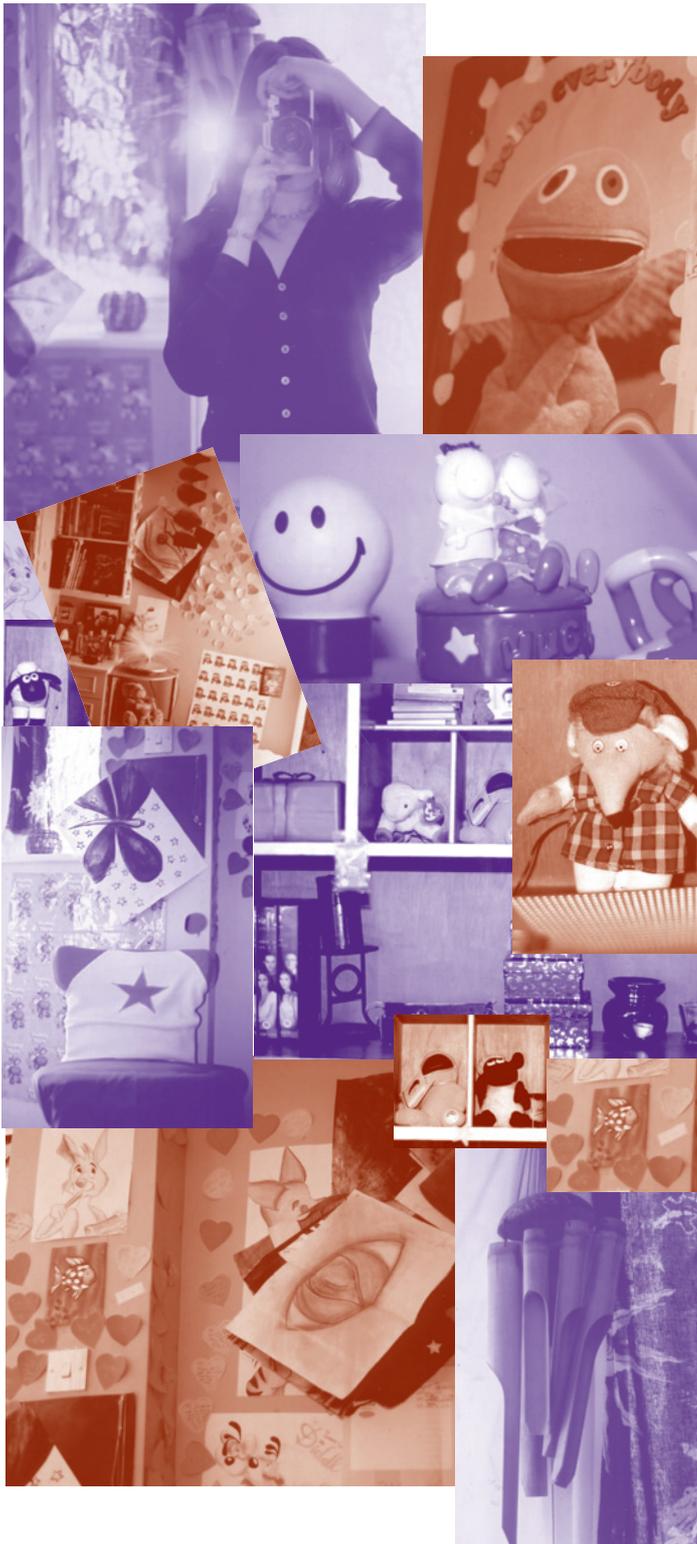
Nye adds: 'I feel alive for the first time ever. I look forward to the future, and getting on with my photography later this year. I don't think about ME much now. It's been tough but I don't expect a medal or anything! I just get on with my life in a positive way.'

Nye's website is:
www.skinnyimages.com



MY SPECIAL ROOM

THE GARAGE!



When I tell my friends 'I live in a garage,' I am only slightly bending the truth.

Converted to a room, it is marked with my invisible signature, a capsule of my world. My cave, my boudoir, my studio, snoozelum, personal concert hall and gallery.

When inside, anything is possible. If hope or calm are swept away by darkness I lie low until the tide of solace brings them back to shore. Then, I can exit again, cautiously embrace what is outside.

The garage is my service station. There I gain fuel and let off steam. Reversing in, putting my engine to rest, locking the doors, securing the hand brake, removing my keys. Resting my fan belt and tires until my windshield demists clearly enough for the next journey. Gently prizing open my own door to reveal a little more of what is inside. Of me.

My paintings hang loose from silver tacks; images generated from within my head. Pastels, watercolours, acrylics and charcoal, they await transfer onto canvas. Emotive art therapy, I make my own posters.

Day glow post-its remind me of my dreams, goals and 'To Dos'. Yellow speech bubbles. Pink hearts within a heart upon one wall. One giant collage.

On some I have scrawled inspirational quotes:

Life is a journey.. Take a coffee break.

The layout of my garage changes frequently and evolves constantly but seems to remain always a reflection of where I am.

Sazza Holmes

2003 BIRTHDAY INVITATION TELL US ABOUT YOUR ROOM

Now the secret's out early! Whether you've had your birthday or not, why not tell us about your special room? (We've another secret invitation coming up for the rest of the year's birthdays.)