

The Young ME Sufferers Trust

2006-1

£2-95

Vision

INSOMNIA - DON'T LOSE SLEEP OVER IT

Dr Darrel Ho-Yen

TEACHER TRAINING ON ME/CFS

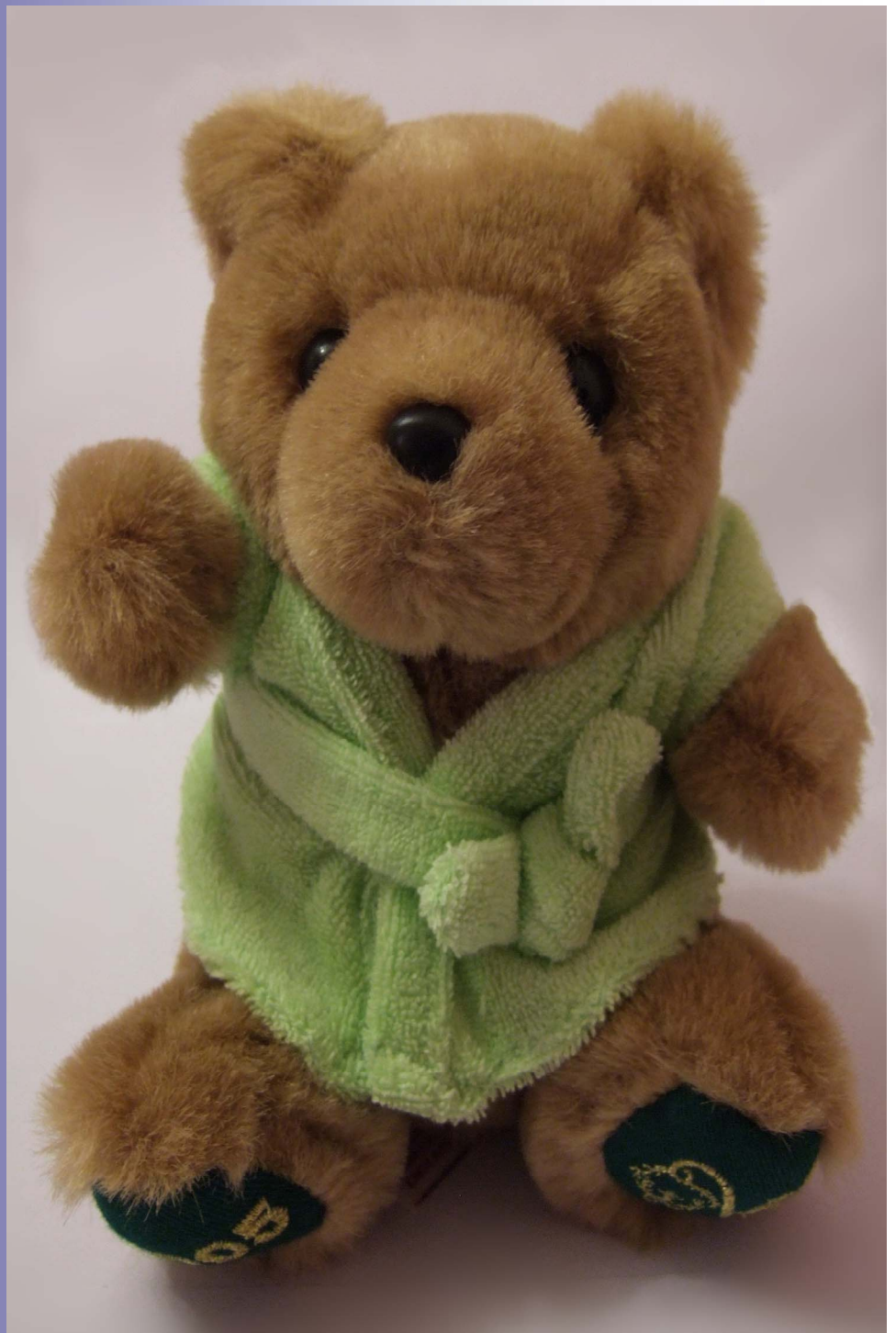
Tymes and Nisai to provide
live online courses

THE TYMES TRUSTCARD EVALUATION

'It is a must'

THE BRIEF

Psychiatrists still in denial
on home-based education



Now in full colour at www.tymestrust.org

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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

Founder Patron	Lord Clement-Jones CBE
Patrons	Earl Howe Barbara Windsor Shirley Conran Terry Waite The Countess of Mar
Friends Patron	Lady Elizabeth Anson
Chair of Trustees	Keith Harley
Trustees	Jennie Whitlock Sally Player Alec Western Margaret Ross
Executive Director	Jane Colby
BWKT	Mark Colby
Address	Tymes Trust, PO Box 4347, Stock, Essex CM4 9TE
Website	www.tymestrust.org
Advice Line, Enquiries	01245 40 10 80
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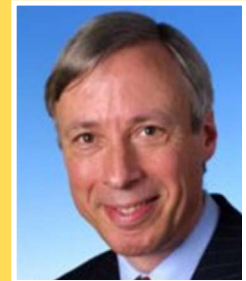
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Cover : 'Look! A Heffalump!' said William

Our Patrons



Lord Clement-
Jones CBE



Earl Howe



Shirley Conran
OBE



Lady Elizabeth
Anson



The Countess of
Mar



Barbara Windsor
MBE



Terry Waite
CBE


Vision - The Project

Children with ME, despite their illness, show great resilience of spirit through the difficulties they have to face. Society could learn a great deal from these young people. Throughout this issue of *Vision*, you will find examples of their letters and emails, many thanking us for our help. We try to publish your messages when we can and if yours is not here this time, we are sorry - we ran out of space!

Of course, we have also needed to cover problems that need to be faced in the fight to ensure that better services are provided to children with ME and their families. In our evidence to the Parliamentary Select Committee on Special Educational Needs (page 16) we have needed to be quite forthright. However, we work with many professionals on our Professionals Referral Service who are shining examples of good practice, such as our Exams Officer, our Social Services Manager, our Consultants and our GP. We are keen to recognise doctors, teachers and others who understand ME and to welcome them onto our Professionals List.

This is an especially busy time for the Trust, with the many other projects in which we are also involved. Our Executive Director is on the PRIME steering group and is also giving evidence to the first oral hearing of the Gibson parliamentary inquiry into scientific research on ME; we are taking part in the process of developing the NICE guidelines on the management of ME; we are developing new publications for the Trust's website; and we are working on teacher training proposals.

Having attended a Department of Work and Pensions benefits meeting, we have rejected the amended benefits guidance as unsuitable, as in our opinion it will lead to many young people having to go to appeal, and we have strongly requested that a second meeting be held at the DWP.

 I am pleased to be able to announce that our research study with MERGE has now begun. This is the first ever biomedical research into CFS in children and was also contributed to by Search ME. If you have taken part we would be pleased to hear about your experience.

Our Executive Director will be one of the speakers at the CFS/ME conference organised by Invest In ME, which takes place in Westminster on ME Awareness Day (May 12th).

You may notice that sometimes we use the term CFS, sometimes we use ME, and sometimes a combination of the two. The Trust uses the term ME as a matter of

policy except where the context requires another term *eg* in direct quotes from other texts or when using the names of official organisations, publications or projects. We are supported in this

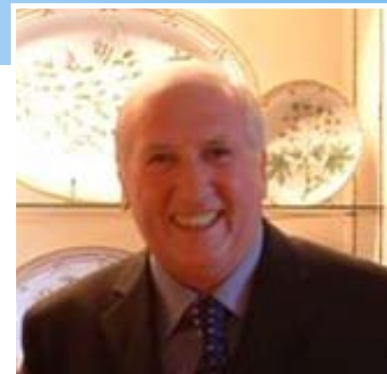
policy by doctors and other public figures who do not consider the term Chronic Fatigue Syndrome adequate to describe the potentially severe neurological condition originally named 'ME' in *The Lancet*.

The renowned microbiologist and ME specialist Dr Elizabeth Dowsett, who has been working on a new survey with the Trust, is among these professionals. She once commented on how important it was for children and young people to have enjoyable activities provided for their long hours in bed. That is something we try to offer as part of *Vision* - and it is good to hear from you when you have managed to do them! Keep writing to us.

Kind regards,

Keith Harley

Chair of Trustees



Keith Harley

Invest In ME

are pleased to present

The CFS/ME Conference 2006

An update on Clinical Diagnosis,
Research Trends and Educational Support
for CFS / Myalgic Encephalomyelitis

with presentations by

Professor Malcolm Hooper

Dr Byron Hyde

Dr Bruce Carruthers

Jane Colby

Professor Basant Puri

Dr Ian Gibson MP

Friday 12th May 2006

One Birdcage Walk, Westminster, London

Email: meconference2006@investinme.org
Telephone: 02392 252365 or 01603 701980

Full CPD Accreditation

Meet Our Patrons



I am pleased to report that, as a result of the meeting between myself, the Trust's Executive Director Jane Colby and Chair of Trustees Keith Harley with Schools Minister Lord Adonis, liaison is now ongoing between

the Department of Health and the Department for Education and Skills. This is with regard to a serious and widespread problem concerning the procedure for granting home tuition and other support by Local Education Authorities.

Lord Clement-Jones CBE
Founder Patron

The Countess of Mar

One of our patrons, the Countess of Mar, is now a member of Dr Ian Gibson's parliamentary Group looking into scientific research on ME. At the first oral hearing of the Inquiry on 18 April, The Young ME Sufferers Trust, together with eleven other individuals and organisations, gave a presentation on the priorities as we see them.



Membership of the Group on Scientific Research into ME consists of:

- ◆ Dr. Ian Gibson MP (Chair)
- ◆ Dr. Richard Taylor MP (Vice-Chair)
- ◆ Ms. Ann Cryer MP (Secretary)
- ◆ Rt Hon Michael Meacher MP
- ◆ Dr. Des Turner MP
- ◆ Mr David Taylor MP
- ◆ Lord Turnberg
- ◆ Baroness Cumberlege
- ◆ The Countess of Mar

At the oral hearing, we advised the Group that the Trust has co-funded the first ever biomedical research in children, now taking place. We presented the latest compelling evidence that ME is a persistent viral infection related to polio myelitis (ie of the virus family

known as enteroviruses) and recommended that certain actions be taken.

Our recommendations for research are:

That an enteroviral study be set up as suggested by JKS Chia in his review *The role of enterovirus in chronic fatigue syndrome*, J. Clin. Pathol. 2005;58;1126-1132

That ME/CFS be made notifiable in schools - staff as well as pupils - in order to demonstrate the pattern in schools; there are mini-epidemics and clusters (see *The Brief* page iv).

That all previous work on ME epidemics over the decades, eg during the whole of the twentieth century, be revisited; it has been sidelined in the adoption of the unsatisfactory name Chronic Fatigue Syndrome

That there be further study of cognitive impairments caused by ME/CFS

Dr Elizabeth Dowsett has suggested that a microbiologist should be invited to assist the Group in some capacity and we have added this to our recommendations.

We shall of course be publishing our presentation in full.

Dr Ian Gibson MP will be addressing the ME Awareness Day conference (see page 3).

Shirley Conran

Do you have a penpal? I do! I am so lucky because my penpal is Jane Colby. I phone her when I can't stand it a minute longer, and she phones me when she is down in the dumps (which is rare). Luckily, we are never 'down' at the same time. Jane reminds me of everything that is going well in my life, of everything I have to be grateful for. She also reminds me that the black fog will pass.



If you haven't got an ME penpal, why not post your request via the contact form at the www.tymetrust.org website? State your age and nearest town, because at some future date you might arrange a meeting, if you don't live too far away! It was a very happy day when Jane Colby eventually visited my home in London.

In The Spotlight

The Tymes Trustcard Evaluation



'The Trustcard has helped. It makes teachers aware that this child has ME and they have taken more interest to find out more about it. It is a must.'

Have you got yours?

'My daughter wants to say a big thank you for the Tymes Trustcard, which has made a huge difference.'

'It has been helpful because if I get stopped in the street you can explain why you're not at school.'

'I haven't yet needed to use my card, fortunately. But it has provided me with a sense of security and confidence when walking around the school. I know it's there if I need it.'

'I was able to get permission to go to the toilet.'

'I could get my dinner quicker.'

'I was allowed to go to the nurse.'

Most cardholders find teachers are willing to support their use of the card, but we will do our best to help if you have a problem.

In 2002, the Bishop of Sheffield presented the first ever Tymes Trustcards to a group of our members in the area. Designed to help protect the health of young people with ME in school or college, the card was endorsed on its launch in the House of Lords by Education Minister Baroness Ashton, by Earl Howe, by our Founder Patron Lord Clement-Jones, and by the Secondary Heads Association, now called Association of School and College Leaders (ASCL).

Assistant General Secretary Bob Carstairs said:

'Children with ME need to have their illness recognised [...] We are happy to endorse children being in possession of this card.'

What is the Tymes Trustcard?

It's a 'pass card' signed by your Head Teacher. It says that you have permission to use the facilities you need, or to obtain assistance.

Why do I want one?

If you can attend school, you may meet teachers who haven't been trained in the needs of someone with ME. We know young people who have simply decided not to ask for what they need, or given up half way through explaining. We know how you feel.

What can it be used for?

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

What else comes with the card?

We send you a pack including a personal letter from us for you to give your Head Teacher.

What does it look like?

The card is small and can go in your wallet or bag.

Does it matter what type of school or college I go to?

No.

How do I get one?

Ring, write or email us to apply.

what you think

Dear Keith,

Thank you so much for Bobby Bear - he was a great surprise. He will guard all my Other Bears on my bed.

Emma Gray (my mum Adele wrote this for me)



'Ere Sarge, we're in the mag again. Are we celebs now then or wot?

No lad. And stop fidgeting.

Dear Mr Harley,

Today, I received a Winter Bear from yourself. It is very cute and cuddly. It has come at a good time because at the moment I have a bad Virus Infection. It keeps me company when I'm feeling unwell. I have called him Fudge. I have introduced Fudge with the rest of my bears. He is settling in very well. I would like to say thank you so much for sending him to me, he has come to a good home.

From Katy Lagden



We have found the website incredibly helpful, as has our GP and my daughter's school. I was also very pleased to speak to the mother on

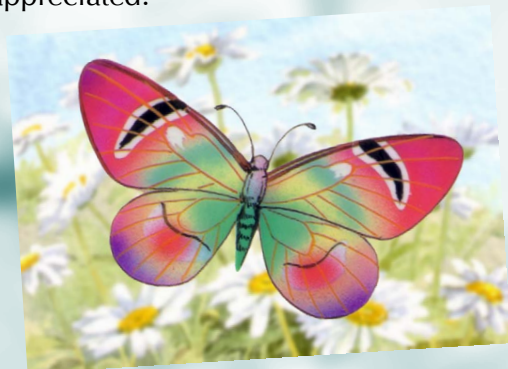
your Advice Line. As a parent, I didn't feel quite so alone. We look forward to our Welcome Pack.



Thank you so very much for the beautiful butterflies which arrived on particularly bad day. They really cheered me up, and looking at them on my window from my bed will help me dream of seeing real butterflies in my garden in the summertime. You are very thoughtful and it's much appreciated.

Love, Sarah Hill

We still have some colourful butterfly window stickers if you'd like some for your bedroom. Write, or ring, or send us an email using the Contact Form at www.tymestrust.org.



Thank you ever so much

for the postal order as my main prize in the Shirley Conran writing competition. I have put it towards the price of an earring and necklace set that I bought from QVC shopping channel on TV - they had a 'silver day' and silver/white metals are my fave, so I got it then. It arrived today and is lovely! It's a dragonfly, with mother of pearl wings.

Thank you again so much, it's really appreciated.

Lots of love and best wishes from

Hannah Churchward



Thank you for the cute birthday card -

I really appreciate that. Its lovely. Also, thank you for the nice light clip-board prize which you sent me. I like to do little puzzles while in bed. So it's really helpful as well as being a nice sunny colour. :-)

I wish you well and I hope that you have a wonderful day, today. Thanks again for everything.

Rosslyn Carlyle from Orkney

I hope through the work of the ME organisations things have moved on a bit since we were dealing with the fear of a 'Munchausens Syndrome by Proxy' scenario but I am sure it is still a dreadful thing to deal with as a parent. I think the most valuable bit of advice you gave me was to give my son the space to deal with the illness in his own way even if sometimes that was difficult to watch as a parent!



Please tell Mark that we are delighted with Vision's 'new look', he has done an excellent job...the colour version on the internet is BEAUTIFUL - I SO enjoyed reading Vision....have been reading it every night before bed and during the day while in bed. Thank you. It is so good to know we are not alone.

From Maria in South Africa

PS I am happy to let you know that we were able to send a donation to Tymes Trust via the website. This is wonderful as it makes payment easier.

I'm just writing to say how fantastic I think your magazine is. It has a good balance between serious articles like latest research and more light-hearted articles, such as competitions which we can all enter. Readers' poems are good too and it's great that our articles can be included.

Now that I'm better than I was a few months ago, and am beginning to tolerate having the curtains open for short periods to let the light in, I'd like to request one of the window stickers please.

Best wishes to everyone.

Sophie Baggs from Wiltshire

We'd love to have some new poems for the next Vision.



I love getting Vision and reading about other people and what it's like for them. I've missed out on so many things because of being ill and I bet other people have too.

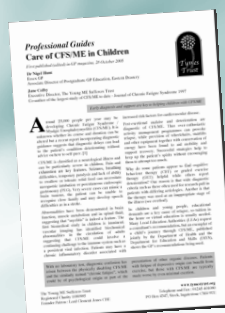
After receiving the *Young Hearts* book, I was inspired to write more poetry. I've now written fourteen and counting.

You know how you learn a new lesson every year? Well, this year I learnt 'Life may get you down but you can't let life keep you down.'

Katie Anne Evans



I've just seen the article from GP Magazine, 28 October 2005. (I asked my GP to save it for me.) I just wanted to say well done - I think you and Dr Hunt did a brilliant job. I especially like the big quote specifically distinguishing CFS/ME from fatigue of depressive origin. Although the title refers to children, it is clear that the points have general value and can be applied to adults too. FANTASTIC work.



Best wishes,
Jacqui Footman

You can read this article in 'Professional Guides - Care of CFS/ME in Children' (concise information for GPs - only two pages) at www.tymestrust.org.

I just wanted to write and say what a fantastic job you did last night on the radio. You got across all the information that they cut out of the TV programme I did, and lots more beside!

I can't believe how many people called up and the calls they did take were really representative of life with ME.

It was interesting to listen to Nick, the presenter, who obviously went through a conversion on air as to begin with he sounded very sceptical.

Fingers crossed it helps lots of people and that they get in touch.

Clare Wade

Clare and her family were featured on Look East. Congratulations for all your effort in the interview, Clare.



Whenever you write in or email us, don't forget to say if you'd like to be quoted in Vision. It means a lot to us to know what you have found helpful - and it also helps us to plan. Send us a photo as well if you can!

CHLOE HALSTEAD INVITED SEB FOR CHRISTMAS

*BUT HIS INVITATION GOT HERE JUST TOO LATE FOR THAT
SO HE WENT TO STAY WITH HER AFTERWARDS!*



To Seb

I really love your page Seb I think you're very nice and I would like to invite you to come to my house for a few days as I feel really ill all the time. A visit from you would cheer me up a lot.

We are having a fantastic meal at Christmas. The dessert will be great but I won't tell you what. It will be a surprise if you come.

You can come on Christmas Day or any other time that suits you. Please reply by sending a letter to my address in Scotland.

Love Chloe Halstead, Aged 13

PS Mum found hundreds of your friends on the window, peeping in.



Thank you for letting Seb come: he really enjoyed his stay and wrote a diary. I was so thrilled when he arrived and my little sister Amber loved him too.

Seb really looked after me and we had a great time together.

Love, Chloe.

xxx

DAY ONE Phew, I've only been here an hour and already I've nearly been eaten by the cat, recycled, and got lost in Leah's (Chloe's neighbour's) hair.



Five star, naturally

DAY TWO I enjoyed sleeping in my own house that was decorated for me. Then we went out and had a great meal. I had everything on the menu. Yum.



Me in my supercar - actually Mark gets all his ideas from me

DAY THREE Took part in a rally round the house, had my own car. I won against a Siberian tiger named Prowler. When Chloe had her rest I played with him and his friend Rajar.



DAY FOUR Chloe was ill so I didn't do much. I looked after her and was treated to 3 doughnuts. I didn't know I was only meant to have one.

DAY FIVE Went to Kircudbright and met a few highland cattle.

DAY SIX Went to the beach and did Sudoku together.

WHAT HAVE YOU BEEN DOING?

DAY SEVEN Time to go home. Said goodbye to everyone (even the cats, who gave me a nibble on my leg). Prowler and Rajar said that I was to come again.



Yehea!

Heaven Sent (edited highlights)



Anthony Welsh became ill aged eight and a half years. A new member of our 26+ Group, he has been writing his story, called 'Heaven Sent'.

My story revolves around my struggle with ME. This is one of the most serious illnesses in

society but it angers me to say that I don't believe that is how it is seen, either by the general public or by the medical profession. I still think they have a long way to go before they wake up to this devastating scourge on people's lives. Just ask a young person of school age who has been confined to bed, unable to walk around, except with the aid of a wheelchair.

My early memories are hazy but I do remember the unbearable stomach pains. My mum thought I had appendicitis; being a former nurse, her medical knowledge was good. The doctor suspected glandular fever but tests proved negative. A consultant paediatrician thought it might be 'in the mind.'

ME is not a mental condition or something that's just in the mind. There are some who will still tell you this. It is both unhelpful, unwise, and frankly, quite offensive to every ME sufferer.

Anthony improved, but relapsed aged 12. As he grew older he says he pushed himself too much.

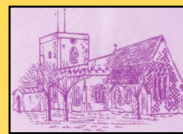
I remember having a season ticket at Everton. We were playing at Goodison Park against Arsenal. As usual, the plan was a weekend in Manchester seeing old mates and a Saturday afternoon in Liverpool watching the football. In reality, the whole experience was becoming an increasingly titanic struggle. Somehow my determination had carried me this far, but this weekend was going to be different.

Before I even set off, I felt dreadful and was physically sick. No problem there, I thought, because that had happened before. I never felt well before I set off anywhere. Usually I managed to get through, but not this time. When I arrived I went dramatically downhill. Unless someone has experienced this illness and been in the same situation, they tend to say, 'Oh yes, we've all been there.' Well, they haven't. I've

had people say to me 'Oh, we all get a bit drained sometimes.' This is possibly the most infuriating thing they can say to anyone who's been there, or still are. The next day I put up the white flag and headed home. Everton lost 1-0 anyway!

Anthony is now much better. He accepted his ME, took advice and helped his body to heal.

The Trust has children and young people on its books from the age of three upwards. We try to reflect the experiences of everyone. Send us your photos and tell us what you have been doing.



Every Christmas, the choir of Redbourn parish church (where Frances Goodchild's dad, Jonathan, is the organist) joins the local Round

Table in a house-to-house collection.

'The proceeds go to several charities, and this year one of our charities was the Tymes Trust.'



My husband David sells organic meat and had a table at a Farmers Market. He decided that all the sausages would be sold for Tymes Trust so we were able to display



leaflets and posters. He had a good market; I enclose a cheque for the Trust.

Best wishes,

Mary Hampton

David's organic beef and pork can be bought from Willow Hall Farm at Wix, Manningtree, Essex.

www.willowhall-organics.co.uk

IN ASSOCIATION WITH
amazon.co.uk

We would like to thank all of you who remember to go via www.tymestrust.org whenever you buy things from Amazon. Without paying a penny extra, you are making a helpful contribution to the Trust's work.

Meet The Team



Susie Jayasinghe

Artist
Age 38

If you look at ‘Things 4 U 2 Do’ on page 12, you’ll see my caravan, where I live with Ranjith, my husband, and my son Bruce, who’s nearly nine years old.

I trained as a sculptor, then did ‘sculpture for touching’, hand-crafting books with pages made of embroidery, collage, illumination and other media. I taught art and karate for three years. Then I went travelling the world. I was into Buddhism (that started off with the karate) and was going to be a

Buddhist nun in Sri Lanka, when I took a break from the temple and met the man who would become my husband.

My caravan is right next to an oak wood. Every Spring it is carpeted with bluebells. Having chosen this life for myself, I then discovered that I have a French Romany circus family background! I remember being fascinated by wagons when I was Bruce’s age. My passion at the moment is Flamenco dancing.

Huge thanks...

...to Fatima Celestino, who ran the London Marathon in 4 hr 25m to support the Trust. Can you spare a little something to add to the total raised? It will go toward providing the next issue of *Vision*.

‘See the girl run the London Marathon with both knees in straps!’ says Fatima. Ouch!



I think Fatima’s commitment to TYMES is marvellous!

Rosie Shorter
Focus Group Member

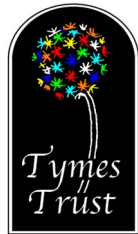
Newsflash

We are delighted to announce an expansion of the Tymes Trust/Nisai Education Partnership:

Tuesday 5th September will see the first online ME/CFS training seminar for teachers

to be given by former Head Teacher Jane Colby using Nisai technology. The seminar will also be open to other professions; send to us to get the details for your own teacher or doctor.

The number of free places for over 16s in the Nisai Virtual Academy has been significantly increased. Up to 2000 places have now been granted by the Learning and Skills Council. For more information, telephone 020 8424 8475 and ask for Preya or Andy. Explain that you are registered with Tymes Trust. If you are under 16, you can ask them about funding by your Local Education Authority.



Accepting the 2005/2006 Award from Essex Community Foundation’s Millennium Fund

Essex member Michelle Cross, her parents and sister Abigail attended the presentation ceremony in Chelmsford with Chair of Trustees Keith Harley and Jane Colby, Executive Director of the Trust. This Award has helped us in providing information to all our Essex members and their families.



Michelle Cross and family with Keith and Jane accept the cheque

What's got 48 legs, 12 noses and can't type?



A deluge of dogs, that's what. We have a software problem.

Remember Trusty - the only hibernating dog in the world? Spring has arrived, and with it, so have Trusty's Friends and Relations. First one turns up (hello little fella, what do you want then?) (go ahead, it's ok) (alright, you guard the keyboard while I go make a cup of tea) and then eleven more (well ok, you guys can watch, but I need that trackball) and then they all want to get involved (hey - I said whoa - come on guys, at least let me save first - well I s'pose I've got a backup - sigh).

Help! It's chaos. There's no room for them here, and for ages this issue of *Vision* was covered in virtual pawprints. I think one just tried to bury a bone in one of the speaker grilles. At least I hope that's what he was doing. They all need homes. Now! And perhaps with a comfy sofa to share with someone who needs a cuddle.

Don't all rush at once! But if you'd like to offer a home to one, write or email using the form at www.tymestrust.org (if you're not well enough, your parents can do it for you). Send us a photo of him in his new home and we'll publish it.



Insight

Pain is a common symptom of ME but is not easily treatable. Even strong painkillers are not very effective and have unwanted side effects. Now it turns out that there may eventually be hope that we can train our own brains to 'modulate' pain.

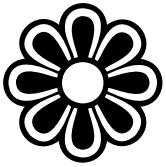
Describing the research at Stanford University in California, *Times* correspondent Mark Henderson wrote: 'Scientists in the United States have successfully taught eight patients to reduce pain from injuries by showing them live scans of their brains while they performed a set of mental exercises. [...] The study suggests that it may be possible to train people to change the way in which the pain centres of the brain process painful stimuli, making the perception of pain less intense.'

More testing is needed, but early results seem to be promising. As the patients watched the scans, they did mental exercises to train the brain to process pain in a different way, so that they would feel less pain. The scans meant that patients could watch the effect that their thoughts were having on brain activity. They could 'concentrate on changing its activity'. They were

encouraged to think of the pain as if it were actually a relatively pleasant experience and over a period of time they began to be able to change their pain level.

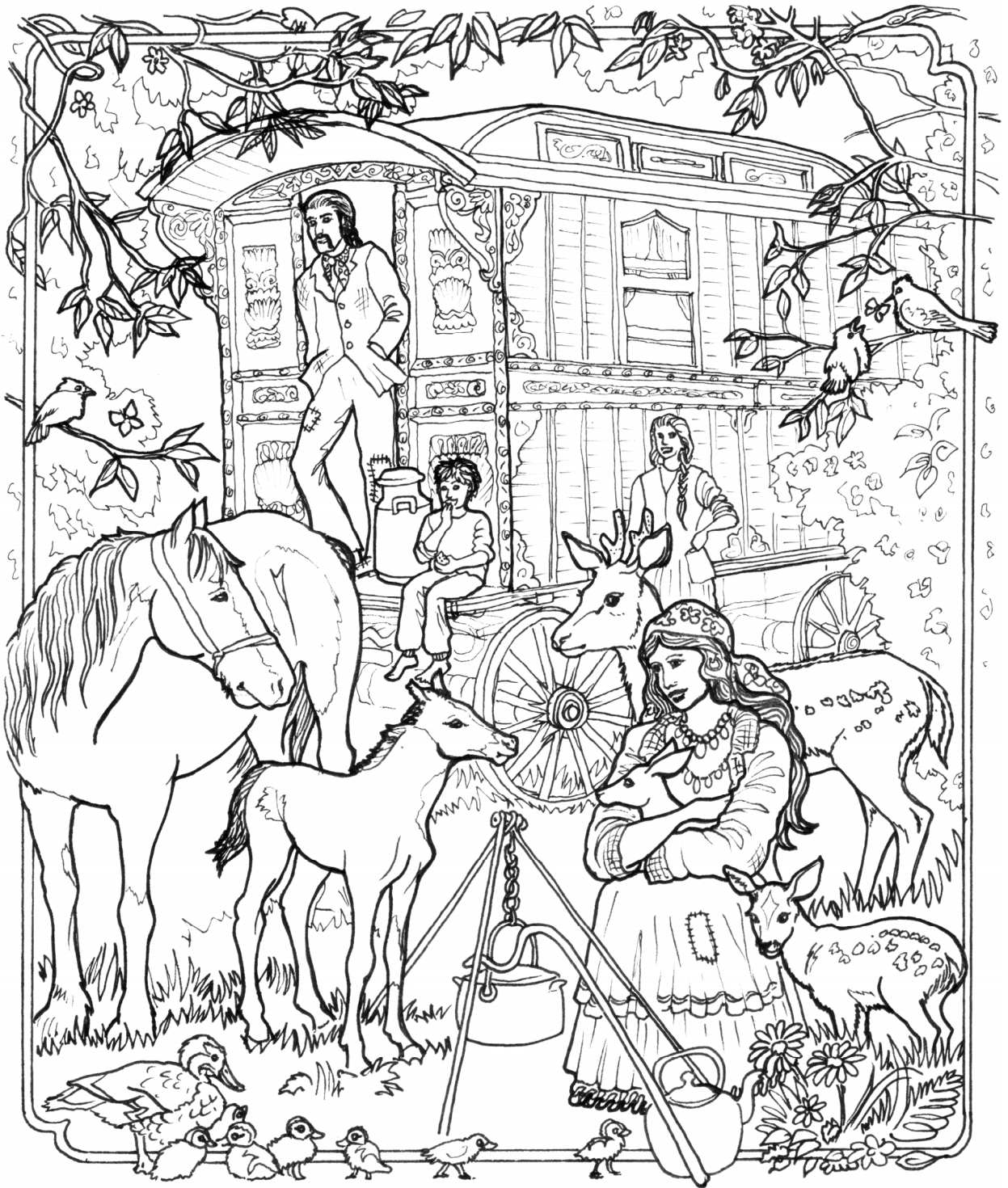
The researchers did not know how this was done, since no-one really knows how people control their brains to produce an action. However, it worked for all eight subjects, five of whom said their pain had reduced by 50%.

One patient said she was imagining 'little people digging out the pain, or I'd think of snowflakes.' In control experiments it was found that only the patients who were actually shown the images from their brains experienced an improvement in pain symptoms. In Summer 2004, the Trust published a feature on visualisation technique by Dr Darrel Ho-Yen called 'Seeing's Believing', and a companion piece on the placebo effect. Perhaps the underlying principle is that if we trust that something can make a difference – in this case, because we can see the brain scans that prove it – the wish becomes a reality. 'Did we just design the world's most expensive placebo?' commented Dr Mackey.



U 2 Do

Things 4



We hope you'll enjoy colouring Susie's Caravan. If you'd like to send your work to us, why not colour in a photocopy so you don't have to cut up

your magazine. If you include a large (A4) stamped addressed envelope we'll send it back to you. We'll give as many prizes as we can.

Ask someone else to help, if you're not well enough...

Read about Susie in 'Meet the Team' on page 10.

Name

Age

Address

Postcode

COLOUR SUSIE'S CARAVAN



Company

*When I have to sit and rest
 I understand it's for the - - - -
 When the sun is far too bright
 I have to shelter from the - - - - -
 I go out when I'm feeling strong
 And try not to stay out too - - - -
 But when I need to lie in - - -
 I have an extra one for Ted!*

Find the missing rhymes. We'll send you a little prize you can use in bed! Remember to count the dashes - one for each missing letter.

DO YOU LIKE READING?

FREE audiobooks for members of Tymes Trust



Listening Books : The National Listening Library is a charity that provides a postal audio book service to anyone who has an illness or a disability that makes it impossible or difficult to hold a book, turn its pages or read in the usual way. Now members of The Young ME Sufferers Trust can apply for free membership.

Contact us for the special form if you are interested.

Quotes-U-Like

*I would be unstoppable...
 if I could just get started.*

*I try to take one day at a time...
 but sometimes several days attack me at once.*

From Eleanor Ward

Can you send us some Quotes-U-Like?

OPEN DAY AT WESTLANDS GARDEN, NURSERY AND TEA ROOMS

Trustee Sally Player and her husband Keith are holding another Tymes Trust Open Day in Essex on Saturday 8th July. If you would like to come, write in for your personal invitation! www.westlandsnursery.co.uk



CLOUD DRIFTER

A poem to illustrate. Send your picture of clouds to us if you'd like a prize.

*I've tuned in my senses
 Sharpened my eyes
 From my window I see
 Clouds emerge and arise.*

*They gather and float
 As if drifting downstream
 Form images of creatures
 That are not what they seem.*

*The sky changes appearance
 As I wish that I could
 Seems content with itself
 As I know that I should.*

*The more each cloud moves
 The faster it's gone
 Evaporated in time
 To let form a fresh one.*

Sarah Holmes

Over her years with us, Sarah sent us many poems. She wrote this one when she was 18.

Can you write a poem for us?

Insomnia - Don't Lose

The Western world is full of people who cannot sleep. Yet sleep is energising, and the more energy that is gained in this way, the more energy is available for physical and intellectual activities – and for healing.

Sleep has been described as the great restorer of the body. Sleep is an attempt by the body to make itself better. Avoidance of sleep delays the repair of muscles. Many patients are aware of muscle and joint pain, know that they need repair but still try and avoid 'too much sleep'. One should not be afraid of sleep, but instead help the body by increasing the hours of sleep.

The brain also requires sleep. It requires time for renewal and reorganisation of information acquired during the day. Brain function is more profoundly impaired by sleep deprivation than any other organ of the body. We are all aware of our tremendous reduction in brain function when we do not have enough sleep. It makes sense that the brain needs sleep, because it remains on a 'red alert' state during the whole time it is conscious.

How often have you been told not to take a nap 'or you won't sleep at night'? This is simply society's way of telling us to be 'normal' – in other words, to conform.

In 'normal' practice, our routines of life demand conformity and it is not generally practical to 'live within the rhythm of the brain' and take a nap whenever we are sleepy. But it does seem to be the ideal, 'power-napping' having been recognised by big business as promoting efficiency. In the same way, eating a snack whenever one is genuinely hungry is more natural than sitting down to three substantial meals a day, timed by the clock, with nothing in between. Yet the 'three square meals a day' myth is still perpetuated. Grazing (taking snacks at intervals during the waking hours) can help to maintain steady blood sugar levels and avoid highs and lows. Napping is opportunistic and makes use of the times when your brain sets you yawning, telling you it's time for a refresh so as to maintain optimum concentration and optimum healing.

Try telling commuters not to nap on the train! And how did Ellen MacArthur get round the world without total disaster to her or to her boat? On 20-minute naps, for the whole duration of her trip.

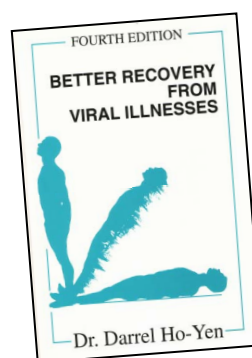
insomnia

Symptoms such as pain, feeling hot or cold, twitching and itching can all cause insomnia in ME. So can the jet-lag effect of the sleep cycle reversing itself, so that night seems to the brain to be day. This can manifest itself like an exaggeration of the person's natural rhythm; some are naturally 'morning people' and others 'night-owls'.

Concentrating too hard for too long just before settling down can prevent sleep. Finding an unwind routine that's good for you can help, but remember that you may wake again in the night.

The theory that we should all sleep at exactly the same times does not admit of the infinite variety of human beings and the patterns that suit them. The holiday T-shirt proclaiming 'I don't do mornings' may strike a chord here...

Try not to get too hung up by being wide awake, fed up and uncomfortable, perhaps even distressed or frightened, while everyone else is asleep. Although noise and light can interfere with sleep, in moderation they can be your friends. Low volume background chat or music, a gentle bedside light, these can be reassuring and help to distract from pain and fear. Experiment.



Dr Darrel Ho-Yen is kindly making his book *Better Recovery from Viral Illnesses* (Fourth Edition) available to Tymes Trust members at the previous cost of £14.00. Send to the Trust for the special order form.

Also for your doctor on the care of young people with ME (at www.tymestrust.org):

The Doctor's Guide to ME in Children and Young People by Dr Alan Franklin

Care of CFS/ME in Children by Dr Nigel Hunt and Jane Colby

Sleep Over It

by Dr Darrel Ho-Yen and Jane Colby

incorrect sleep myths

X *Good sleep means instant sleep the moment the head touches the pillow with total unconsciousness for eight hours.*

Sleeping throughout the night is learned behaviour for modern living. Babies do not sleep through the night, and in terms of survival it makes sense to awaken frequently. With illness, there is often reversion to a more natural sleeping pattern with frequent awakening.

X *Good sleep means no vivid dreams*

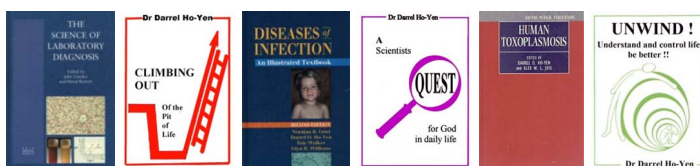
Everyone dreams. Experiments in keeping people awake result in 'waking dreams' or hallucinations. Vivid dreams are not unusual in this illness, if alarming at times. Try not to let them frighten you into staying awake. The more your brain rests, the more it can recover.

X *Good sleep means waking totally refreshed*

You only feel totally refreshed if you wake at the time in the natural cycle when sleep is at its shallowest. Anyone who wakes at the deepest stage of sleep can feel terrible and not refreshed. In addition, the body needs more sleep if it is ill, so trying to cut out naps will aggravate any feeling of sleep deprivation.

X *Drugs will do the job*

Sleep medication doesn't work well in ME. Various remedies have been tried with no conclusive results. In 2002, a study by Williams et al into the use of melatonin and also of bright light photo-therapy concluded that neither worked better than a placebo (neutral substance). Self-help is likely to be the best option, especially given the potential hormonal side-effects of melatonin.



Other books by Dr Ho-Yen

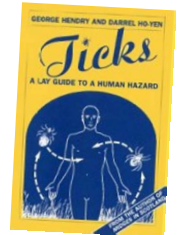
Lyme Disease

false alarm

Dr Ho-Yen is an international expert in Lyme Disease, based in Scotland.

He is concerned at the many false positive results being obtained from private laboratories and advises that people should have these results checked by the NHS.

Another microbiologist has lodged an official complaint against a private hospital. Lyme Disease, carried by ticks, can be treated by antibiotics, but in chronic cases where they are ineffective, management is the same as for ME. Long term antibiotics, says Dr Ho-Yen, are not helpful.



ME Clinics

we want to know

In our experience so far, the new clinics are varied in their helpfulness. Some have called themselves 'chronic fatigue services' whereas others are 'ME/CFS services', which is more encouraging.

The bottom line is the kind of support they offer. We haven't been sent much positive feedback yet, unfortunately, but do keep us informed of the good and the bad.

If you wish to see a clinic started up in your area, we advise contacting your local ME support group and working together, though the initial government money has now been allocated.

Download the Trust's report *Our Needs Our Lives* from www.tymetrust.org/tymespublications.htm to use as evidence for the type of support that children and young people need. Examples from the survey:

- ◆ 92% did not consider that psychiatrists should automatically be involved in the care of children and young people with ME.
- ◆ 79% wanted the clinic to provide support for carers.

This report was produced with a grant from the Local Network Fund and Essex Community Foundation.

Special Educational Needs

our evidence to the UK parliament Education and Skills Select Committee



The UK parliament Education and Skills Committee

is a cross party group of MPs formed in 2005 and tasked to examine 'the expenditure, administration and policy of the Department for Education and Skills and its associated

public bodies'. The Committee is currently undertaking an inquiry into special educational needs, looking at the following issues:

- ◆ Provision for SEN pupils in 'mainstream' schools: availability of resources and expertise; different models of provision.
- ◆ Provision for SEN pupils in Special Schools.
- ◆ Raising standards of achievement for SEN pupils.
- ◆ The system of statements of need for SEN pupils ('the statementing process').
- ◆ The role of parents in decisions about their children's education.
- ◆ How special educational needs are defined.
- ◆ Provision for different types and levels of SEN, including emotional, behavioural and social difficulties (EBSD).
- ◆ The legislative framework for SEN provision and the effects of the Disability Act 2001, which extended the Disability Discrimination Act to education.

The Trust calls for urgent specialist training for teachers of children with ME/CFS and is submitting the following explanatory evidence.

1 ME - also known as Chronic Fatigue Syndrome or ME/CFS - is the biggest cause of Long Term Sickness Absence from School, as first discovered by Dowsett and Colby (1997 *Journal of Chronic Fatigue Syndrome*). This is the largest study of ME ever undertaken. Dowsett and Colby studied a school roll of 333,024 children and 27,327 staff. They also found clusters of the illness.

2 There is now abundant research evidence that this is an organic illness and not a psychological disorder, yet many children with ME are still not being offered education suitable for their needs, and to enable them to perform to their ability in examinations. They suffer widespread discrimination against their disability.

3 Children with ME fall into two categories. They suffer from a chronic illness but they also have special educational needs because of its effects upon both the body and the brain. They often need part-time or home-based education, curriculum modifications, and special arrangements for examinations such as extra time, rest breaks and sitting the exam at home. These assist children with ME to perform to their ability when seeking qualifications and minimises the educational disadvantage caused by the effects of the illness on the brain. The authors of a paper revealing further objective evidence of cognitive dysfunction recently said that sufferers 'appear to have to exert greater effort to process auditory information as effectively as demographically similar healthy adults. Our findings provide objective evidence for the subjective experience of cognitive difficulties in individuals with CFS.'

4 Section 19 of the Education Act 1996 requires Local Education Authorities to make suitable provision for all children and young people who cannot attend school by reason of illness. But there is a significant overlap between medical and special educational needs in this illness and it is often virtually impossible to separate the two. Schools have a Duty of Care as well as a duty to provide suitable education for children with special educational needs. In ME these two overlap, since too much mental concentration can produce physical relapse and physical relapse means that the child can no longer study. School attendance or inappropriate

educational demands are a key cause of relapse; this results in further educational disadvantage.

5 Two years ago, a study by The Young ME Sufferers Trust (*The Forgotten Children* 2003) found that 87% of 126 young people it consulted had struggled for recognition of their needs and 81% had had to change schools to gain such recognition. Sadly, the Trust is still receiving similar reports.

6 Such is the concern amongst young people and their families that this year, young members of the Trust, through its study *Our Needs Our Lives* (April 2005) have asked if new ME/CFS clinics being set up with NHS funding will support the Tymes Trustcard, which is a school pass card system set up and run by the Trust with the support of the Secondary Heads Association. The card protects the needs of young people with ME in school. However, we have no evidence as yet of this being done.

7 The Young ME Sufferers Trust has also set up a partnership with a private firm Nisai Education to provide a Virtual Classroom for secondary age children unable to attend school due to ME - a scheme which we were pleased to launch in 2004. They have secured 50 places for those over 16 to continue receiving free education. More government and LEA support for such virtual education schemes is needed, especially as it is not home-based education that isolates these children, it is the nature of their illness. The virtual classroom enables interaction with other pupils whom they may later meet, as well as increased educational achievement and support for recovery.

8 At the moment, evidence from families strongly suggests that both the special educational needs and the medical needs of children with ME are not being sufficiently addressed by schools and Local Education Authorities despite many government and professional publications.

8.1 In 2001, The Dept for Education and Skills stated in its statutory guidance *Access to Education for Children and Young People with Medical Needs* that ‘pupils who are unable to attend school because of medical needs should be able to access suitable and flexible education appropriate to their needs’.

8.2 In 2002, Chapter 5 of The Chief Medical Officer's Working Group Report (Dept of Health) stated that: ‘nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning.’ Jane Colby was a member of the Working Group on Children.

8.3 In 2004, The Royal College of Paediatrics and Child Health stated that ‘as a general rule reintegration should be slow and cautious’ and drew attention to the Dept for Education and Skills recommendation that a resumption of education in whatever form should be planned in a way which ensures that children and young people do not feel under pressure to study. It refers to the virtual classroom as a means of providing continuing education for children and young people with ME.

8.4 Unfortunately, parental reports suggest that these and other recommendations and statutory guidelines are too often disregarded. Denigratory remarks have been made, and continue to be made, together with suggestions that children with ME do not have genuine special educational needs.

9 It appears that LEAs are unwilling to make Statements of Special Educational Need for children with ME. Recommendations under the Code of Practice are often inadequate. The Trust has published the first ME/CFS guidelines for Educational Psychologists (September 2005) but believes that teacher training in the needs of pupils with ME is urgently needed. The Trust has run such courses, after which teachers have felt much better equipped for their task. A teacher who had attended one of the Trust's courses won the first Thorntons Award for supporting her pupil.

10 Schools breach their Duty of Care if they insist on school attendance or fail to make suitable provision and thereby make the child worse. Discrimination issues arise when special educational needs are not provided for and special arrangements for examinations are not offered or the school refuses to apply to the Examinations Board. OFSTED is expected to identify a lack of suitable provision for these children but parents report to The Young ME Sufferers Trust that in their view these deficits are not being picked up in inspections.

10.1 The Trust holds on file a host of letters, emails and completed questionnaires from parents describing unkind and ignorant treatment at the hands of teachers and others in the education profession. To quote from a parent who recently contacted The Trust: ‘When I spoke to the head of the sixth form on Friday afternoon she said there wouldn't be a problem if she went to school! It staggers me - I think that most people cope by pretending that it can't really be a “proper” illness.’

10.2 The entire paragraph from this parent's letter reads: ‘We all have to put up with general disbelief in

You Tell Us

the condition. It has been made very clear to me in recent months from other parents behaviour round me that they think my daughter is unbalanced, school phobic, exam phobic, neurotic and suffers from panic attacks. The headmaster did admit to me recently that the school had never had a student who over the years had missed so much school. She was the only one in her year who did not attend the prom organised by her year on Saturday evening. They didn't bother to invite her in the first place, and she probably was not well enough to be there, but it would have been good to have been included. I know that this is considered by the other children in her year as yet another example of her being odd and not fitting in. One parent told me that no-one at school believes that she is ill because sometimes she gets to go out and do interesting things. We didn't receive the information from school about the sixth form, because she had been left off the list, and when I spoke to the head of the sixth form on Friday afternoon she said there wouldn't be a problem if she went to school! It staggers me - I think that most people cope by pretending that it can't really be a "proper" illness.'

11 Lack of specialist knowledge, educational techniques, suitable courses, facilities and examination arrangements is still turning children who could potentially obtain qualifications into failures with few or no qualifications to their name. What is almost worse is that many believe it is their own fault.

12 The Trust is calling for urgent training programmes for teachers to give them the understanding and skills necessary to ensure that government statutory guidance is indeed followed for these children, whose condition is unique in its mixture of medical and special educational needs.

The Trust would be happy to assist, by offering expertise or advice.



The Trust believes that Local Education Authorities, lecturers and teachers need specialist training in ME. We are working to see that this happens.

Frances's ME began in September 1999 when she was 8½, although, looking back, we can now see that her health had



Frances, aged 12.

She was bed-bound for 3½ years

been in decline for quite a while. By September she was exhausted, complaining of headaches and many other unpleasant pains, and was quite unable to leave the house, let alone go to school. She appeared to have swollen glands, and after a few weeks began to feel constantly nauseous. After two months off school, a trainee GP referred us to a local paediatrician. The latter was polite, though somewhat cold in his manner, and diagnosed CFS, with the proviso that a few more tests, eg blood tests and an abdominal scan, should be done.

I thought no more about this consultation, but I began to be uneasy about the amount of pressure that the school was putting on us to return to part-time attendance. I discovered, by chance, that the paediatrician's written report to the doctor had been passed by her - quite wrongly - to County Hall. I obtained a copy of the report from the surgery and found that CFS was not mentioned! Instead I was accused of 'enforcing' symptoms on my daughter (and there was much more besides).

Fortunately an experienced and sympathetic GP took us on and wrote to the school immediately, confirming that Frances was suffering from CFS and was not able to attend school. We were able to engage Dr Alan Franklin¹ privately as our consultant, and send his report on Frances (April 2000) to the school.

Despite this, we received a letter from Social Services in September 2000 to say that we had been investigated under the Children Act. It

¹ You can download a copy of the late, and sadly missed Dr Alan Franklin's *The Doctor's Guide to ME in Children and Young People*, produced with Tymes Trust, from www.tymestrust.org.

transpired that a report had been sent to Social Services by the headmistress of the school conveying doubts as to whether Frances was genuinely ill. Fortunately the letter from Social Services also informed us that the case had been closed because our GP had confirmed that Frances was ill.

We took action against the Health Authority for the defamatory statements in the paediatrician's report, as well as for his deliberate omission of the diagnosis he had made at the consultation; but although several of our complaints were upheld, the matter was never satisfactorily resolved.

Kathy and Jonathan Goodchild



Frances with her brother Matthew on his 18th birthday



I am now in my 3rd year with the OU after an aborted attempt at a full time degree at a brick uni (who were very ME unfriendly). I have just attained my first uni level

qualification, in the form of a Higher Ed certificate in Maths, and am a third of the way to my degree.

Also, interestingly, I went back to the Colchester County High for Girls to finish my A levels aged 29. It was the happiest 2 years of my life and I came out with 3 A grades and a student of the year award!

Sarah Stokes

As you see, we are happy to publish contributions from our 26+ Group. What would you like to tell us?

ME/CFS Guidelines for SEN Assessments

Naomi Burgess, a chartered educational psychologist with experience of ME, and Jane Colby, a former head teacher and severe ME sufferer, have produced the first comprehensive set of guidelines for educational psychologists who plan and carry out special educational needs assessments for children with ME. The guidelines published by The Young ME Sufferers Trust are available free of charge at www.tymestrust.org.

From the news section of The Psychologist

My name is Hannah Williams and I am 11 years old. I have had ME since I was 3 years old but I only had my diagnosis in 2003. At my primary school, none of my teachers or my friends understood my condition. If it wasn't for my mum I wouldn't have gone to hospital and my teachers wouldn't have known anything.

Since I am at secondary school I'm not doing music, which I find hard with my chest and my breathing, as I also have asthma. I am missing some lessons and relaxing in the chill out room.

I get very tired when I do too much. I have bad headaches and get very painful legs. I am writing this in my living room and haven't been to school at all this week and I have not been well. My friend's sister also has ME and I was shocked to find out.

I didn't want to accept anything at first but I then realised that I had to stop trying to be 'normal'. My mum had very similar things to me when she was a child. She didn't go to hospital or anything, as I do, and she still gets tired, some leg pains and bad headaches.

My advice I would give to those who have ME - I would listen to your body and what it's telling you. And pace yourself or you will go right back to the start of getting better. That's the key to recovering from ME.

THE Question

What should teachers be taught about ME?

In every issue of *Vision* we are now asking for your views on a particular topic. As you know, whenever we seek our readers' views, we always act on what you tell us.

Please list any particular aspects of ME which you feel it is especially important for teachers to know about, and please tell us about anything teachers have done for you which has been particularly helpful. Write to The Question, PO Box 4347, Stock, Essex, CM4 9TE

SEB'S MANOR



Sebastian Says

Till today, I didn't know how the magic pens I've been sending people worked! It's very rare for me not to know something. As you know, I'm very modest but let's face it, normally I do know everything. But as they say 'When all else fails, read the instructions'...

For secret messages, write your secret message with the white pen. To reveal messages, colour over with any pen. The message will magically appear.

After that it got complicated, but there are loads of effects you can get! There are 9 one-colour pens, 9 colour-change pens with different colour caps, and 3 white pens.

I've taken charge of choosing prizes, so let me know if you want magic pens as your prize for any of the competitions.

The Very Cool and Famous SEB
Order of the Golden Web
(and Prizemaster)

Thank you so much for the prizes. They really cheered me up! I can't send you a photo as I am sensitive to light.

Love, Vicky

If you need cheering - you know what to do! Send me something for my page or enter a comp.

Julia's Colouring Competition

Prizewinning entries from
Gemma, Helen and Jodie

*I have just got home
after five months in
hospital and have
really enjoyed doing
this - thank you.*

Gemma Barton (23)



Helen
Rogers-Smith (10)

VIRTUAL HOLIDAYS

Claire Wade couldn't just go on holiday like me, so she came up with something else:

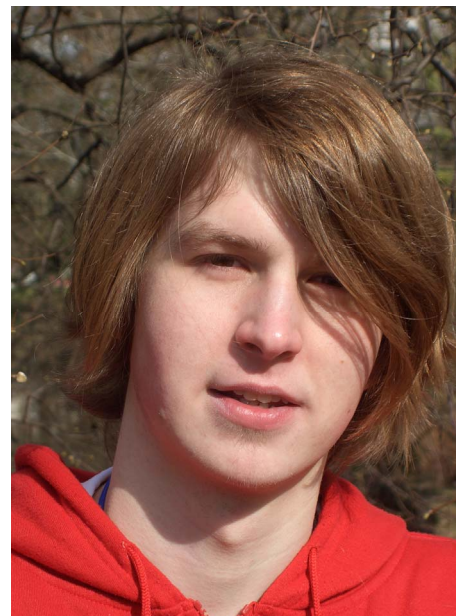
We often can't travel in reality but in our mind we can travel all over the world! To make a truly successful virtual holiday you need a bit of an imagination and a determination to have some fun. I've put together four virtual daytrips, one to the Great Barrier Reef in Australia, one to a Woodland Cabin in Iceland, one to the Sahara Desert in Africa and one to an English Stately Home. Nothing can make up for a real holiday; but when travel isn't possible a virtual holiday is the next best thing!

www.virtualholidaycompany.com

Thank you for all my wonderful prezzies. My Bobby Bear (my cat is called Bobby!), the art set I won from Julia's Art Competition, my magic pens. They were brilliant! To say thank you I have drawn you a picture.

Happy Easter to everyone at Tymes Trust.

Luv Jodie Halliday (13)



David Loxley-Blount
www.wazzuup-music.co.uk

Mum Jan writes: David is almost 17 and was first ill at the age of 9. He has Aspergers too.

David hasn't been able to attend full time school and has had many battles with his LEA to secure educational support. Jane helped him write an educational life plan, on the basis of which he studied GCSEs and other public exams sequentially. (He couldn't have done them at the same time!)

So now he has two 'A's and two 'B's at GCSE, and a collection of ABRSM and Guildhall Music Certificates. He's also completing his European Computer Driving Licence. He's working carefully towards AS level Music, GCSE English and several ABRSM Music Exams.

The Special Needs Advisor at Trinity College of Music advised David that with ME it may be difficult to cope with the performance requirements of most music degree courses, and suggested music composition. This Easter three of his works are being premiered!

Would you like to be in my photospot? Send me some photos and some stuff about you.

SEB'S COMP

Last time:

Well done to everyone who won something for counting how many times I appeared in the last *Vision*!

Here's my New Comp:

To get something from my Treasure Chest (or magic pens) tell me the name of my friend on the front cover of *Vision* (with his paw in the air).

Clue: it's printed in italics, somewhere in Vision!

Can anyone tell me the name of the pair on the front of the last *Vision* too? If you haven't got a copy, you could open the colour copy on the website and check there.

When you send me your answers, let me know if you want me to print your name.

Don't forget your address - and say if you would like the magic pens, or a surprise from the Treasure Chest.

Send to : Seb's Comp, PO Box 4347, Stock, Essex, CM4 9TE



*Eggsellent Jodie
(eggsactly as I eggspected)*

*It don't matter
Young or old
Grab your courage
And be bold*

*Send your pictures
Send your rhymes
Send your stuff
To me at TYMES!*



Surprises from my Treasure Chest go to everyone who sends me something for my page!



A birthday letter from ...

Thank you so much for the birthday card you sent me - it means a lot to know that other people know how I feel and are thinking of me.

I had a wonderful day as my two best friends from school and I went to the health spa at the Alton Towers Hotel, near to where I live, for a very relaxing day. Rhiannon drove us there. She had an aromatherapy back massage and Elly spent loads of time in the swimming pool and sauna. I had a mini makeover - a facial, manicure and make-up lesson. It was really lovely to see them again as I had not seen them since I left school after a very disappointing year at AS level (year 12) when I had to give up all of my courses after my health went downhill.

This year I have started two part-time courses at my local college. It does not wear me out too much and it has given me a lot of extra confidence in meeting



and talking to new people. I look after my two rabbits, Brandy and Bridget, with some help. Mum usually cleans them out for me, especially when it's cold and she and my brother Will sometimes feed them for me if I am not feeling up to getting up at my normal time. It always makes me feel good about life to know my two bunnies are waiting for me to go and see them to give them loads of fuss and attention.

Loads of love to all at TYMES and thank you for thinking of me.

Sarah Harris

PS I thought the enclosed cards might be useful for sending to Tymes Trust members on their birthdays.



Thank you Sarah. It means so much to our members to receive a personally signed card on their birthday.

If you have enjoyed your birthday card, perhaps your family could send us one for someone else!

Hi All, and Jane, thanks for the birthday card!

I just had to tell you about my fantastic CFS-friendly birthday party a few days ago. I'd have written sooner but I've been recovering. In all honesty I'll be recovering for a while yet, but it's only once a year. We're all encouraged not to boom-and-bust, but even the OT conceded that once in a while allowances can be made.

The preparations started in advance, planning all sorts of party nibbles. Where possible I wanted things to be as low-preparation as possible - for instance rather than making jelly, I got ready-made pots of jelly. The worst bit was during the morning, having to sit still and rest on the sofa while my mum and boyfriend put the finishing touches to the food - I was so excited and I wanted to join in!

Part one of the party was held in a nice riverside pub

twenty-odd miles from my flat. This was partly to see friends who lived nearer there, but mostly so that I could have a 'half-time' sleep in the car on the way home for an hour while still having a decent length party. I should probably add that my boyfriend was driving, not me...

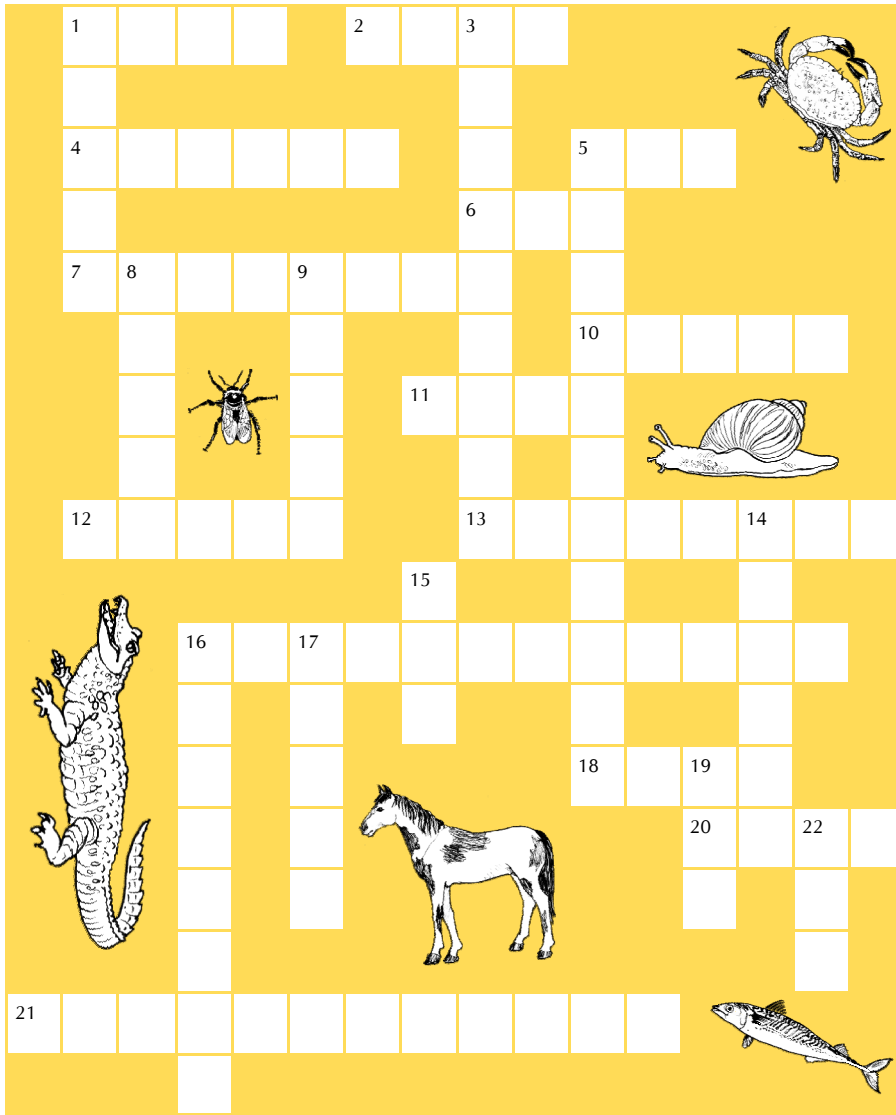
Back home and I was ready for part two. My sister was on guest-greeting duty and lots of my friends made the effort to pop in at least for a little while, as well as about six of us who were there for the whole thing. No alcohol - the CFS doesn't like it and I was never that fond anyway - but plenty of laughter. I did need the occasional rest in my bedroom and I'm completely broken now, but I feel it was worth it - I had a birthday to remember.


(oh - and I was 24)

Mary Bates

All Creatures Great and Small

by Lydia Francis



- Down**
- 1 A pony is a small version of this (5)
 - 3 This bird has the largest wingspan in the world (9)
 - 5 An extinct flying dinosaur (11)
 - 8 In Dr Doolittle a 'pushmi-pullyu' was a two-headed one of these (5)
 - 9 In The Lion King there are three of this laughing animal (5)
 - 14 This is a weird lizard (anagram : gimnau) (6)
 - 15 A titchy wolf with an orange bushy tail (3)
 - 16 This is a prickly customer (8)
 - 17 This type of bear lives in cold places (5)
 - 19 Toowit toowoo toowit toowool (3)
 - 22 I'm not being left out! (3) 

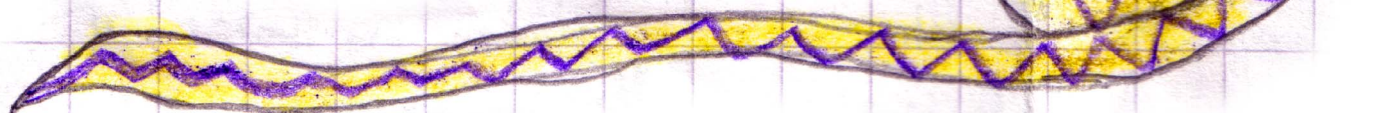
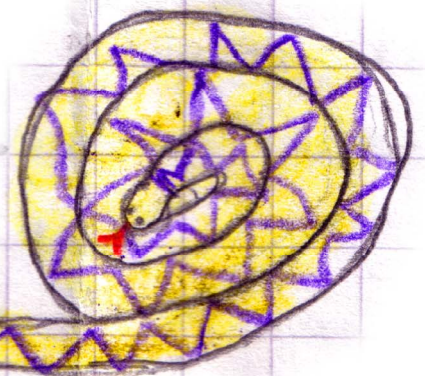
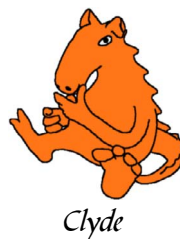


Across

- 1 This large bunny's name is much like hair (4)
- 2 12 across and 17 down are two types of ... (4)
- 4 A smaller version of 1 across (6)
- 5 Babe was one (3)
- 6 This small insect lives in a nest (3)
- 7 According to Pooh Bear, this is a Heffalump (8)
- 10 Like 16 across, but with a horn (5)
- 11 This extinct bird was very stupid (4)
- 12 This black and white animal loves bamboo (5)
- 13 This fish should be in the sky at night with the moon (8)
- 16 This guy is almost as heavy as 7 across and loves mud (12)
- 18 This is the king of the big cats (4)
- 20 This insect stings you but doesn't make honey (4)
- 21 The only living dragon in the world (6,6) (Clyde disputes this)

The winning picture for our Africa competition

Well done Kat Langford, for winning the Stripes bag kindly donated by Caroline Higson with your zebra photo. Kat writes: 'We went on a mini safari at Cricket St Thomas (I went in my wheelchair) and there were two beautiful zebras right next to the train as we went past!'



Bear Necessities



It's got to the point where *Vision* isn't complete without bears. We are considering suggesting to the National Institute for Clinical Excellence that they be provided on prescription.

Name the Bears Competition – to be judged by the Mystery Owner and his bears. Get the family to help. Prizes? Yes, of course!

'So glad to read the letter in *Vision* to Mr Harley, because now I can take comfort from the fact that I'm not the only bear-centric 26+ member. The notable difference, however, is that I'm a guy, which some would suggest makes it more difficult for me to admit to living with bears whilst maintaining my credibility!!

'I agree totally with Sarah (who wrote in last time) about Tymes Trust and the *Vision* mag, which contrasts sharply with the comparative corporate seriousness of some of the others, few of which make any reference to bears. Or spiders...'

Looks like we need to carry the ME Alliance with us on this one...



Leaders of The ME Alliance charities with the 2005 report



For ME Awareness Day 2005, we all worked together to produce the joint report *ME Diagnosis: Delay Harms Health*.

This report can still be downloaded from www.tymestrust.org and is very useful for anyone having difficulty obtaining a diagnosis. Presentation copies are also available.

the trolleyboys triumphant return

I am a friend of Mark's and the partner of Andrea Foster, who has raised money for Tymes Trust through her running. I arranged for my band, The Trolleyboys, to perform a charity gig at Rawreth in aid of Tymes Trust. All who came thoroughly enjoyed themselves and the bank has matched the funds raised. I hope that you will find the money useful and helpful to you in the work that you do.

Stuart Cole

On behalf of 'The Trolleyboys'



And now ladies and gentlemen, it is the distinct pleasure of the management to present to you the evening's star attraction. Here they are back after their exclusive three year tour of Europe, Scandinavia and the sub continent. Won't you welcome from Rayleigh, Essex, the fabulous show band - The Trolleyboys!

Thanks Guys!



Carol Vorderman has sent her good wishes to all our young members!



ME is the biggest cause of long term sickness absence from school. It is a serious, potentially severe and chronic neurological illness. World Health Organisation classification ICD10 G93.3