

The Young ME Sufferers Trust

2008-1

£3-95

Vision

for young people, families and professionals

ME AWARENESS MONTH

Meet us in North Wales

AT HOME WITH THE TRUST

Welcome to our Virtual Open Day

THE COLBY REPORT

Wants your contribution

THE BRIEF

Activity programmes: helpful or harmful?

Diet in ME: is it such a big deal?

The Lightning Process: miracle cure?

View in full colour at www.tymestrust.org



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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

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Patrons	Earl Howe Shirley Conran The Countess of Mar Princess Helena Moutafian Terry Waite Barbara Windsor
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Advice Line Hours	Mon-Fri 11am-1pm, 5pm-7pm
Printing by	Prontaprint, 11 Runwell Road Wickford, Essex SS11 7PS

Our data protection policy is available

Cover : Cuddly Bear Therapy

Our Patrons



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The Countess of Mar



Princess Helena Moutafian MBE

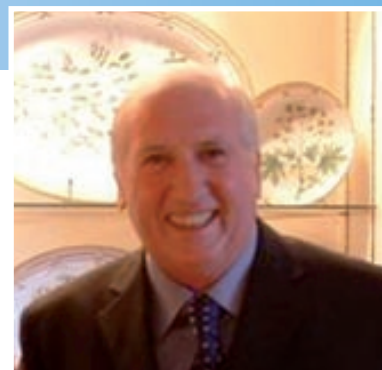


Terry Waite CBE



Barbara Windsor MBE

Vision - The Project



Keith Harley

In modern contemporary Britain all organisations encounter a number of different religions and cultures in their work. Over the years, the Trust has been conscious of the need for sensitivity and understanding in providing services and advice to families from a variety of backgrounds.

Over the past two years, our Executive Director Jane Colby has studied for a university Diploma in Religious Studies, which she has now obtained, having gained a working understanding of the academic non-confessional study of religion.

In obtaining a depth of knowledge of the variety of human religious cultures with their social and educational implications, she has gained particular expertise in world religions and in contemporary experience of religion in Britain.

The Trust's work with children from different backgrounds will, we hope, benefit from the expertise she has gained in this important area of religious and cultural understanding.

So do remember to let us know if you do not want to receive birthday or Christmas cards for religious or other reasons, as we provide this service on a personalised basis, with all cards being hand-signed.

Now let me take you back to the end of 2007, when we sent you an issue of *MiniVision*. Inside was a copy of *The Human Factor*, which discussed the relationship between ME and poliomyelitis, and touched on the reason why, years ago, the viral connection with ME was sidelined, disbelieved and discarded.

This was of course a disastrous move. It contributed to the widespread view among the public and many medical and educational professionals, that ME is merely fatigue - and probably a psychologically based fatigue at that, rather than a serious physical illness. The ripples from that fateful decision are still spreading outwards today, both in the reluctance of many GPs to diagnose, and in the kind of treatment you may be offered.

In *The Human Factor*, you were invited to complete a short questionnaire which is almost certainly unlike any you have completed in the past. It will help with the production of *The Colby Report*. If you have not yet sent for your copy of the questionnaire, there is still just time for you to complete and return it. The more the better - you don't have to be a member of the Trust and you can remain anonymous. Some local support groups are putting this request in their newsletters too, and we hope to hear from some of their members as well as our own.

The most exciting development from our point of view is the potential for a cure in the work of Californian virologist Dr John Chia, whose son developed the illness. We ran part of an interview with him in *The Human Factor*.

Lots of people have read it - in fact it's the most read publication on the Trust's website at the moment and if you haven't seen it, I do recommend that you do. It is on the magazine page of our website.

The Trust's theme for 2008 is the enteroviral cause of classic ME, which we are determined should be properly recognised by the medical establishment. You can help by

filling in the questionnaire and by letting other people with ME, who may not be members of the Trust, know of this project, no matter what their age. And if you'd like to contact your local paper, we can supply you with all you need to convince them that this is a good story!

Kind regards and thank you for your continued support.

Keith Harley

Chair of Trustees

Trust Latest

Advising the Government

The Young ME Sufferers Trust is invited to advise on alternative education provision for children with ME. More details soon.

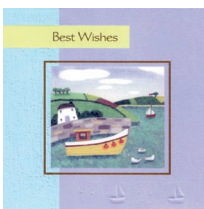
Fri May 16 - Conference *Civic Hall, Connah's Quay, Wales*

At the Clwyd ME Group Conference, Jane explains the ME-polio link and discusses Dr John Chia's discoveries on enteroviruses, diagnosis and cure.

Wed July 16 - Teacher Training *Venue to be arranged*

Jane runs a teacher training event for East Sussex on Wednesday 16 July. Teachers from other areas welcome (contact the Trust).

Sign up for our new Alerts service and you could receive our news as it breaks. See pages 14-15.





Virtual Education Update

advising westminster on best practice

Meeting with Lord Clement-Jones at the Department for Children, Schools and Families

Lord Clement-Jones and Lord Adonis, Parliamentary Under-Secretary of State for Schools, recently arranged a high level meeting for us at the Department for Children, Schools and Families (DCSF).

Many of you will remember that, in his address to the guests at last year's House of Lords event, Lord Adonis expressed support for the Trust's work and presented the first new



generation Tymes Trustcard to our Young Advocate Shannen Dabson. He also asked to be updated on our educational work.

At the meeting, Chair of Trustees Keith Harley, Executive Director Jane Colby, and Dhruv Patel, Director of the Nisai Virtual Academy were able to report that the Trust's partnership with Nisai is increasing children's educational achievement as well as preserving their health and facilitating their improvement.

Nisai Virtual Academy Results

GCSE	2004/2005	53% A*-C	(National Average 51%)
	2005-2006	67% A*-C	(National Average 62.4%)
	2006/2007	72% A*-C	(National Average 63.3%)
A Level	2006/2007	100% A-C	(National Average 96.6%)

Children with ME who are not educationally supported in appropriate ways are not achieving anything like these results and many do not obtain a single qualification. You may wish your son or daughter to be given this opportunity.

Common Local Education Authority Misunderstandings

1 That children with ME need to have been diagnosed before receiving out of school provision

This can take months or even years. In 2006, Lord Adonis provided written confirmation to the Trust that diagnosis was not necessary (otherwise the 15 day statutory limit for providing suitable educational services would be exceeded).

2 That children with ME are only sick and do not also have Special Educational Needs

This means that they are considered only to need short-term provision,

rather than long-term support. Yet a typical bout of ME lasts around four and a half years; for at least two of those years (and in many cases for far longer) pupils are not strong enough to attend school without

- a) suffering a deterioration in health, and
- b) suffering a deterioration in their achievement.

3 That children with ME have a psychological rather than a physical condition

This leads to their commonly being referred to paediatric mental health services and in turn that commonly leads to the view that providing education out of school is undesirable.

Facts for Your School

Children with ME are the biggest group of children out of school for health reasons, frequently needing long-term educational provision in their homes *Dowsett/Colby, Journal of Chronic Fatigue Syndrome, 1997.*

ME is a neurological disorder (*WHO classification ICD 10 G93.3*) seriously affecting the brain and body; processing of information is often severely impaired and effort

(both mental and physical) produces deterioration.

The report of the Chief Medical Officer (DOH 2002) and the NICE Guidance on CFS/ME (DOH 2007) both refer to the requirement for alternative means of education to fulfil the educational and health needs of these children.

The partnership between Nisai Virtual Academy and the Trust is delivering a highly successful interactive virtual education service.

Friends of The Trust



Several years ago, the Queen's cousin Lady Elizabeth Anson launched the Friends of the Trust. As Friends' Patron, she wrote to invite members and others to join and held a reception for the Friends and other supporters of the Trust. In 2007 she attended our celebration of the children's educational achievement in the House of Lords.

We are happy to announce that the Friends are now to have their own Co-Ordinator:

Lady Elizabeth has ME herself and has had for many years. A few years ago, she was kind enough to hold a champagne reception for Friends and supporters of the Trust at her lovely home in London.



The Friends receive invitations to any special occasion that the Trust holds, such as, for example, last year's celebration in the House of Lords, held to recognise the educational success of children with ME using the Trust's virtual education partnership with Nisai Virtual Academy. Nisai Education funded that event, and a great day it was too. Some of you were there and will remember it well.

You may also remember that the original Friends' Co-ordinator was

obliged, sadly, to pull out before she could make contact with everyone, due to her husband's illness. That left the Friends without a Co-ordinator. I have now taken on this role. I am thirty, have been a member of the Trust through my twenties, and decided I would like to help.

Our Friends and other supporters live in different parts of the country, so it's not easy to meet socially and share ideas to help support all the good work done by the Trust. However, I'm now hoping that we will be able to exchange our thoughts about this, because although the Trust is entirely run by people who give their time free, it can't run on air!

I feel sure that between us we could find a way for the Friends to help raise much needed funds from time

to time, to support and maintain the Trust's services to families. We could also, perhaps, encourage others outside the 'ME world' to become Friends of the Trust.

It only remains for me to invite you to become a Friend if you have not yet done so, to invite you to contact me with any thoughts you may



have, and of course to invite existing Friends to write to me and introduce yourselves.

All good wishes

Katie Durben
Friends Co-Ordinator

To join the Friends costs just £10 as a one-off payment.

In The Spotlight the lightning process

I have concerns about the Lightning Process. I'm currently helping someone who was housebound before doing LP in December, found it to have a wonderful and immediate effect and started to get out and about, apparently without adverse effects, had a fantastic Christmas, really believing she was on the mend, but around the end of January started to relapse and has now relapsed to a point much worse than she was before she did

LP, unable even to get a meal; carers have had to be organised, etc. No amount of application of LP or support from her LP practitioner has made any difference.

I've discussed LP with a member of our local service, who is extremely cautious, also knowing of several patients who have had severe relapses, although our service's official stance is to have an 'open mind' and not to discourage patients

from any reasonable approach they wish to try.

Jacqui Footman

We advise caution, remembering that not all people who have been diagnosed with 'CFS' will share the classic ME pathology, so not everyone will respond in the same way to any treatment. You know your own body best.

Jane Colby discusses the Lightning Process in The Brief (page iv).

what you think



Hello, I'm sorry for the delay in contacting you, I've had a relapse so am rather behind on thank yous. However, I had to thank you for the lovely New York bear, I love anything to do with New York so he has pride of place in my room!!! Thank you again, I love him.

Love Vikki George

We know some of you have had relapses. We're thinking of you - try to keep up your spirits.

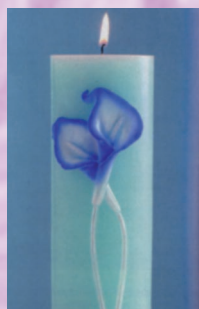
A vigil is being held on 12th May, International ME awareness Day and I am writing to warmly invite you to join us on this special day by lighting a candle and spending some time in spiritual contemplation in support of the ME community worldwide. Details are at www.vigilformeawareness.org.uk.

Holding a vigil raises awareness of ME and serves as a powerful means of encouraging unity and strength of purpose.

With Hope,

Vanessa Mitchell.

We agree that remembering people with ME is a thoughtful way to spend some quiet time on ME Awareness Day. We are joining Vanessa's vigil. You can also hold your own vigil on any day.



I don't normally buy the *Daily Mail* but on one of the rare occasions I did, I noticed your letter [about ME and polio]. It stood out very well. Well done.

Rosemary Lever

If you would like a copy of Jane's piece in the Daily Mail, send a small donation to cover our costs.

Thank you, for yours and the other advisors very personal support, I don't know how I would have survived without you all.

Elaine Charles

You can meet some of our Advice Line Team on page 11.

Firstly, many thanks for Edward's birthday card which we saved until today so he opened them all together. He has few friends being at home and it was a nice surprise to have an extra one.

We also received in the post this morning the results of his Grade 8 Singing exam, and he has passed with Distinction. We are so pleased and proud, it was worth the effort, he took around 5 days to recover the exertion!

He hopes to be taking Grade 7 piano in December and Grade 6 cello soonish, it is difficult balancing school work against his music but when he gets a result it seems worth it!

Regards, Sheila

Thank you for Snowy, he's great and is getting on very well with Chocolate Moose.

Louis Ashburner



Your thoughts and photos are invited for an illustrated book on living with ME, by Natalie Boulton. Some examples are being exhibited in London at the Invest in ME conference on 23rd May 2008.

Some of our members have spoken directly with our colleague Dr Elizabeth Dowsett, retired consultant microbiologist and key UK specialist.

Thank you for putting me in touch with Dr Dowsett. It was amazing talking to her. Thank you for asking Gillian from the Advice Line to ring me too.

I often forget that I am, as Dr Dowsett reminded me, an 'intelligent lady'. I have battled through many things in my

I am writing to let you know that I am able to download *Vision* via the Internet and would like you to save the postage and money in mailing us a copy to South Africa. Please let someone who does not have internet access benefit from our copy. Thank you once again for all you have done for us.

I am very happy to see the enterovirus connection confirmed!

Maria from South Africa

Read about the link between ME and enteroviruses in *The Human Factor* at www.tymestrust.org.

John Chia MD, interviewed in *The Human Factor*, is visiting Britain to talk about the enteroviral link at the Invest in ME conference on May 23rd. Further information and booking facilities are at www.investinme.org.

I know it's quite a while ago now but thank you very much for the Amazon voucher and writing paper set I received for entering the Shirley Conran competition 'What makes me happy?' The voucher went towards buying the *Guardians of Time* trilogy. I loved the first two books, so thank you, I now finally know what happens!

Helen Brierley

life, and I can battle through this. I will certainly halt this demoralization of Kate and me, by ignorant professionals.

I felt like a lone gladiator in a pit of hungry lions, now I realise I am part of a team, and that helps. So thank you again.

Elaine Charles RGN RM

Elaine also wrote us an article, see page 16. Let us know if you would like to speak with Dr Dowsett.

Many thanks for your quick response to my email, I found the information very helpful as we now believe there is light at the end of the tunnel.

I have spent months corresponding with the school and I feel they have treated us like 'bad parents', I knew my child was ill and I could not get him better. The only GP that helped us agreed with PVFS but said it should not, in his opinion, affect his timetable.

I was interested to see your comment on the coxsackie virus, as our complementary

therapist said that was what was affecting Ben and producing the ME symptoms.

I thank you once again as up until now I have had so many doors shut in my face.

Regards

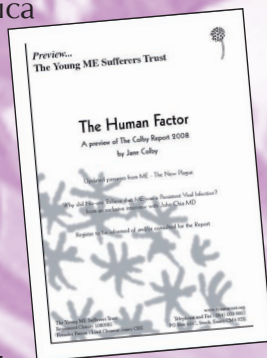
Jackie and Benedict Kittner

*Coxsackie viruses are enteroviruses (gut viruses) and are related to poliomyelitis. To read about the link between ME and polio, read the preview of *The Colby Report* at www.tymestrust.org.*



Lots of love to you and all the young patients. You are doing wonderful things for them.

Betty Dowsett



Thanks for getting back to me personally you are very kind. [...]

I was just having a cry before I checked your email. We finally got hold of your book *Zoe's Win* and I was just reading it because Laura is too ill tonight to look at it.

What can I say ... It's a little book of marvel!!! Thank you thank you thank you.

Yours Rachel and Laura

Jane Colby



Zoe's Win

*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!*

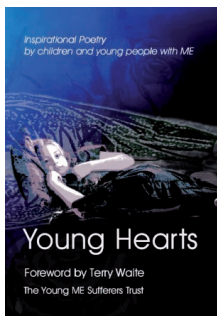
Some of you got amazing exam results through our partnership with the Nisai Virtual Academy.

I would like to thank the Trust for telling everyone about Nisai Education a couple of years ago. I would not have got my A Levels without them.

The first year I got an A for English Literature (78%, 90% and 96%) and also an A for ICT (90% and 100%). I only did ICT the second year as doing two would be too much.

I got 100% for both

Campaigner
Antoinette
Christie, whose
son has ME, wrote a
review of *Young Hearts*.



Young Hearts is a book of poetry which goes to the heart of the suffering of children with ME. It clearly describes the pain, suffering, loneliness and

despair experienced by these children. They talk of life being put on hold, like a video tape stuck on pause, they wait for something to happen to release them from this terrible illness.

From the first poem the young Jade Scarrott writes eloquently in *Light What Light* about the pain experienced from ME, 'Who is screaming all that pain?', 'A little girl screaming, screaming, screaming' and yet despite this she writes of hope when she says 'what's that light at the end of the tunnel?'

In *From Which to Climb* Robin Sansom talks of ME as 'a pit from which to climb'.

Rachael Marshall in *A Friend* talks about the social isolation young people with ME feel, with the loss of friends, and isolation from peers, the hurt they endure on top of their ME: 'They haven't bothered to keep in contact with me', 'But now they all seem to have forgotten me. It hurts.' She describes clearly what

we would all wish a good friend to be, someone 'who'll pick you up when you are down. Someone to help you through good times and bad'. What a loss she is to those friends who have left her behind and not the other way round.

When the thought of being in a wheelchair would be truly awful to contemplate Tommy F Robin speaks of it positively as a way to let him do the things he wants to do, of having fun: 'Being in a wheelchair for ME is not hell, Because I can run as well.'

Sarah Murphy writes in *I Will Win*, 'Will I beat it? Of course I will'. If faith alone can move mountains then we certainly can help Sarah and others like her beat ME by fundraising and researching the h*ll out of this illness until we get them a cure.

To do this book justice I would have to comment on every individual poem, but instead I have decided just to wet your appetite in the hope that you will want to read more and therefore buy this book yourself. Seldom have I been moved more by a book of poetry and been awestruck that the writers are young children who are living with a chronic illness. As a mother of a child with ME it

exams and the coursework! (bragging to anyone who will listen.) My coursework was like a thesis at 500 pages!

Regards, Caroline

To read about our virtual education partnership and its launch in the House of Lords, read *Succeeding with ME* at www.tymestrust.org.

'Surely the fact that those already on this scheme have achieved a 100% A-level pass rate speaks for itself.'

Lord Clement-Jones CBE

'It is our job to see that these children aren't badly treated and do get an education.'

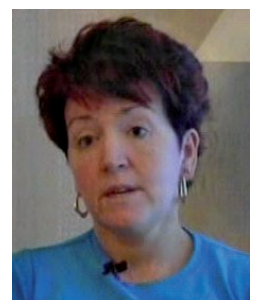
Dr Betty
Dowsett

opens my eyes as to what is going on in his head and what is left unsaid.

Much praise to all of these extremely articulate, talented young people who write with experience and depth beyond their young years. Their creativity should be nourished and made to soar. There is no telling where these *Young Hearts* will go, but one thing is for sure that their presence in our lives is the richer for knowing them. Please read this book.

Antoinette

First published in the newsletter of the Irish ME/CFS Association (a Trust Partner Group), Spring 2008. Do send us more of your poetry. Buy *Young Hearts* direct from the Trust at £7.95 including post and packing.



The Meeting

Once upon a time there was a beautiful magical princess, she lived in a wonderful white castle in the forest. Some days she would like to walk into the local town and look at the people, she never used to speak to them though, as she was scared of them, they were poor and she thought that if she tried to help them in any way they may take advantage of her or even rob her, so she kept her distance from them.



Indra wins a £10 Shirley Conran Writing Award

One day she was sitting in her favourite spot in the forest singing, when her 3 animal guides came to her,

the lion of courage, the fox of thought and the peacock of love. They told her that she should ignore her fear of the people and go into the town and speak to them.

Trembling she headed off to the town to do as the animals had told her. As she got to the town she met an old couple who were very poor and dressed in rags. The princess wanted to run away but the lion told her to be brave and stay there. The fox helped her to talk to the people, always thinking about what she was going to say first, so as not to insult them or hurt their feelings. She found that the people were very kind and loving, and she felt her fear melt away as her love grew for them.

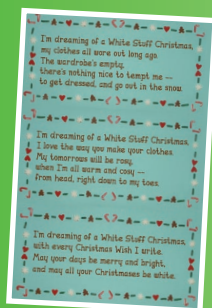
She asked the old couple if they would like to come and live with her in the castle where they would never want for anything or be cold and scared again. At this point the two old people turned into the most beautiful

You might like to colour this small version of our artist Susie Jayasinghe's picture. The large version is in 'Things 4 U 2 Do', Vision 2007-2.



angels. They explained to her that sometimes things aren't always as they seem and that if you help people and give with love in your heart, you never know, but you may be helping an angel in disguise get back to heaven.

Indra Wignall



You are welcome to feature my White Stuff Competition picture in *Vision*. Hopefully it will inspire people to have a go at something creative.



Our coffee morning (cakes, cookies, crafts and 'Grandad's Wooden Toys') raised

It was a major achievement for me, as I'm still in bed most of the day. I didn't win unfortunately, but they did give me £50 for second place - I'm in the process of spending it as we speak!



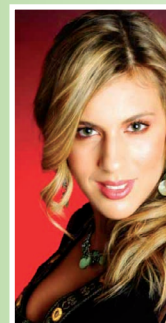
Sophie Dixon

For the competition, Sophie created edible replicas of White Stuff clothes from food! Delicious.

uk.youtube.com/watch?v=sj-87IBFVFE

£225 for the work of the Trust, to which Katy and Ben added £25 each. Fingers crossed that in 2008 a definite aetiology is identified and successful therapy will follow! Keep up the good work...

Lesley Brackston



In an article in *J Lifestyle* magazine, Daliany Kersh described living with ME.



When my ME is at its most severe, I still spend days in a dark, quiet room in pain but not for quite so many at a time.

On my better days, in bite-size sessions, I now surf the net or go out for a short car ride or have my hair washed. There are still many days where I'm unable to do anything but over the 10 years, I've managed to take 3 A-levels by distance learning, achieving an A and 2 B's.

fun raising!

On Yer Bike

Not content with taking Advice Line calls, Katy Brackston's family has also kindly helped the Trust by raising funds. A sponsored cycle ride on Salisbury Plain raised £480 after Katy and her brother had also contributed. Braving the plains were:

Charlie Fraser
Alan Thompson
Jez Cook
Sam Park
John Brackston



Cheltenham Archers Tournament

For the second year running, Cheltenham Archers kindly donated half the proceeds of their recent Tournament to the Trust; 26+ member Anna Linari-Linholm collected the cheque on our behalf.



Anna Collects a cheque for £114.05

The tournament went well. Everyone involved enjoyed it (despite it being very cold and having snow very briefly). I am just glad to be able to help give something back to the charity that has given me so much support and strength over the years.

Kindest regards
Anna Linari-Linholm



Sky Dive

Ami Lindsay did a Sky Dive on her 18th birthday. Ami was close friends with Jade Scarrott, who inspired our 'Young Hearts' book. The folk at her mother's work helped by sponsoring her. Well done Ami.



'Hello - a cheque of £213.50 has been sent out in the post today!'

With thanks
Ami Lindsay

With donations from the Friends, the grand total was £318.50



School

Westonbirt School ran a music and poetry evening to raise funds for the Trust. We understand that the proceeds are over a hundred pounds and counting. Thank you to Sophie Baggs' mum, who inspired it.

Northern Ireland Does it Again

Thank you to Antoinette Christie whose son is a severe sufferer, for raffling hampers and collecting to the tune of £350 to date, to support the Trust's work.

Boot Sale

Shannen Dabson and family are running a summer Boot Sale for the Trust. Could you perhaps do the same? Or even a garage sale? The Dabsons frequently think up new ways to have fun and raise funds. Recent donations totalled over £300.

Remember the Children

Last year's ME Awareness Day concert organised by Remember the Children in Brentwood Cathedral started out as an awareness-raising event. But it also raised over £800 towards further awareness raising by the Trust. We thank the Reverend Philip Joy, Fiona Wall and Colin Pittman and his wife Jackie, whose glorious voice filled the Cathedral.

Meet The Team

Village's Best Kept Secret *Exmouth Journal, 10 April 2008*

'A well-kept secret gave a Lypstone couple an almighty surprise as the village celebrated the pair's community spirit. Honouring 30 years' commitment to the Lypstone Players amateur dramatics society, a party for Daphne and Brian Ridge underwent so much undercover planning, it warranted protection under the official secrets act. The close-knit village kept plans under wraps for two months [...]

Said Daphne: 'We could not believe what a wonderful evening had been prepared for us.' Party co-organiser and Players committee member Sue Mildenhall said: 'Many friends were afraid to talk to the couple in case they inadvertently mentioned "the party"'. [...]

Ceilidh music from local band Off the Square entertained partygoers, who raised £700 for the Tymes Trust charity for young sufferers of ME.

And they didn't tell us first either! We don't usually do a whole page about fundraising but we want to say 'Thank you' to everyone and recognise your kindness and all the effort you put in.

thank you!

Shopping?

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 make a helpful contribution to the Trust's work.



Congratulations!

Our Advice Line Co-ordinator, Jo-Anna Roberts, was last year joined by her mother on the Advice Line. Now it's a family commitment. When Jo-Anna married, we featured her wedding photo. Now we feature a photo of mum Kate's wedding to Ian - with Jo-Anna in the middle!

Get Some Good Advice!

As you know, all of us are volunteers. It is a rule of the Trust that all Team members have personal experience of ME, either through caring for a child with ME, or through having it themselves. They also have a manual with lots of official information. Some of the Team have been with us since the 1990s.

Our youngest Team member is Katy Brackston. She is just 19 and is amazingly confident and good at her job, showing that young people with ME, given the opportunity, can show the rest of us a thing or two.

The Advice Line and Professionals Referral Service number is 0845 003 9002.

Weekdays 11am to 1pm and 5pm to 7pm.



Energy Price Increase

I've written about Energy Price Increases, but instead of tips to help the environment and keep bills down, mine help you save energy. Here are the first ten...

- Use other people's wherever possible.
- Keep things ordered so you don't waste time searching.
- Have doubles of anything important that your ME would be worse without.
- Get someone to buy you a nice box to keep precious things by your bedside.
- Get remote controls for everything.
- Use spoken word cassettes and CDs.
- Watch DVDs in stages instead of going to the cinema.
- Have sunglasses, a pillow and a blanket for car journeys.
- If someone has upset you, bang a pillow before trying to sleep.
- Use an electric toothbrush

Shannen Dabson



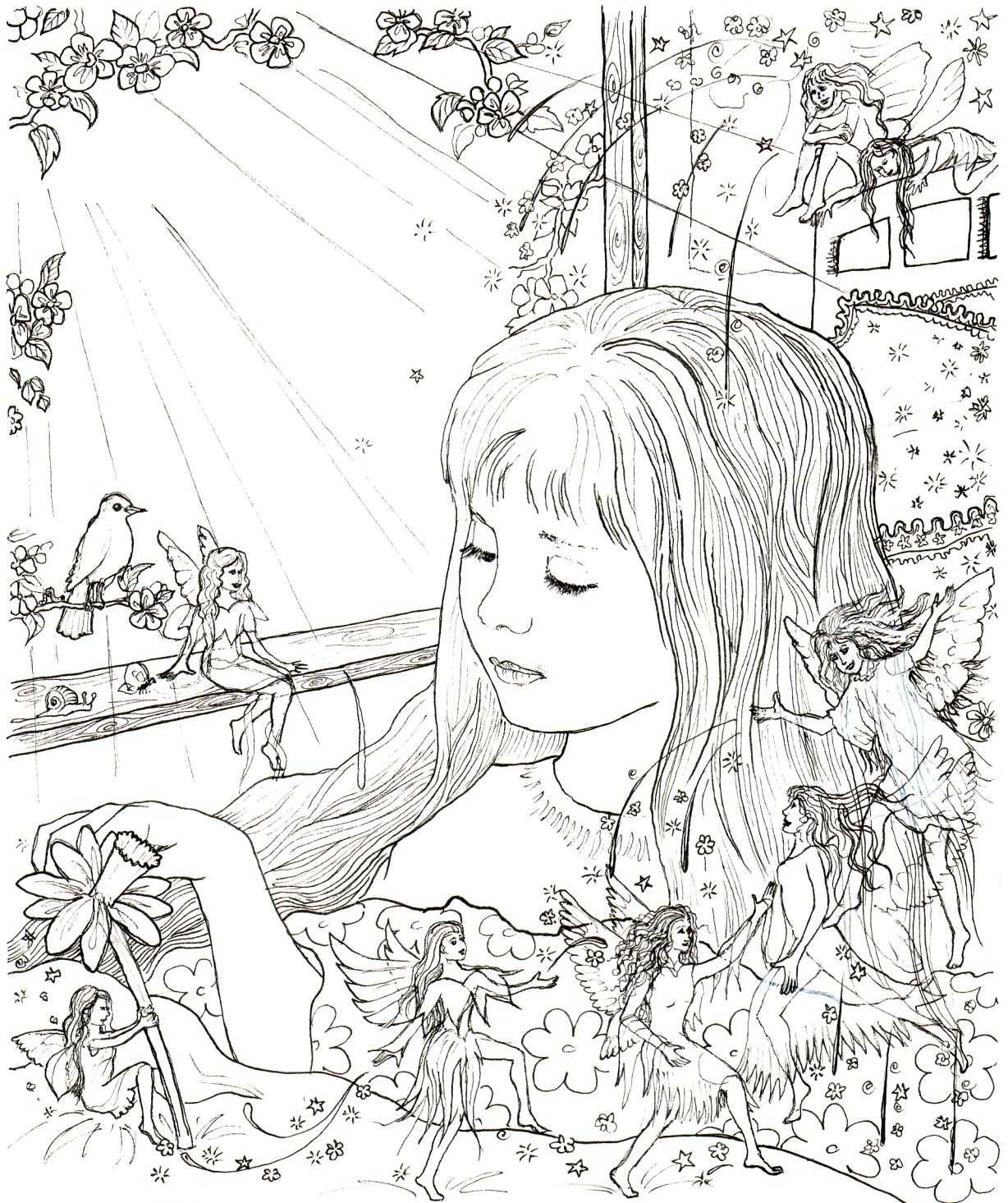
Shannen is the Trust's Young Advocate. Here she presents Zoe's Win by Jane Colby and our poetry book Young Hearts to Karen Swift, librarian at her local library.



U 2 Do

Resident artist Susie Jayasinghe draws you a magical scene to colour

Things 4



While she drew, Susie asked us to play music to set the atmosphere. We played Clannad's *Magical Ring*. Did you know that Sir Arthur Conan Doyle (who wrote the Sherlock Holmes mysteries) believed in fairies, and one of England's most famous horror writers wrote a novel about them? The ancient spelling is faerie. In Irish folklore, the Good People (as they are known) are not always good; they do dark deeds too! But we think these are healing fairies.

Colour the picture for a special prize and we'll print it if we have room. Write us a story about the picture and you could win a Shirley Conran Writing Award. Colour a photocopy if you don't want to cut up Vision. We'll return it if you send us a large letter stamp.

Name
Age
Address

THE GOOD PEOPLE



RATATOUILLE

I've still been entering competitions and recently

won a 'Ratatouille' goodie bag. I was wondering if it might make a good prize for someone? I think the pencil case with stationery might be nice for those who like to write letters; there's also a chef hat, maze game, egg timer in the shape of a chef hat...

I thought the film was really good when I saw it at the cinema. I was never very fond of rats but for my A2 ICT project I had to design a database for Cavy Rescue, who have a rat adoption scheme! I adopted a rat called Becky and fell in love with furries - they are not

horrible at all!

Caroline Higson

To win the goody bag, just write us a good letter! Lots of runner-up prizes.



GREETINGS STAMP..

If you'd like a tiny stamp saying: 'Supporting The Young ME Sufferers Trust' to use for your card collection, we can get you a self-inked one for £5.50, postage included. It also shows our website so others can learn about ME.

OR BUY A SET OF LABELS...

Our new purple flower labels look great on the back of cards. £1.25 per sheet inc P&P (2 sheets for £2).



CREATE YOUR OWN GREETINGS CARD PORTFOLIO!

This idea was inspired by Eleri Messenger. She's been very poorly so her dad sent us two cards she designed last year.

They are Christmas cards, but we're showing them to you now because you could copy her method for anything - birthday cards, general cards or even start a collection for next Christmas!

Cut some nice art paper into small squares. Roughly sketch a tiny picture, then paint it with a very thin paint brush to make a miniature painting. Beautiful!

Use a glue stick to fix it to a folded card.



(You can also buy card blanks from craft firms.)

Spot

I've got a dog and his name is Spot

Sometimes he's happy, sometimes he's - - -!

Sometimes he wants to go to the park

So he picks up his lead with a cute little - - - -

When I'm not well or have pains in my head

He quietly lies down at the foot of my - - -

Sometimes I cuddle him, sometimes I can't

And sometimes we visit my uncle and - - - -

There we relax with tea coffee and - - - - -

It helps me ignore all the niggles and aches.

Spot just plays quietly and chases his ball

He knows that I love him and comes when I - - - -.

Spot makes me happy, Spot makes me laugh

Mum and dad say he's too clever by - - - -!

Find the missing rhymes. Remember to count the dashes - one for each missing letter. We look forward to receiving your answers. Last time, Elizabeth Bell won our Winter Ride 1st prize for first correct entry. All runners up won magnetic calendars and other goodies. Congratulations to everyone!





The Trust is expanding its services with a new initiative that goes hand in hand with Vision. We are very excited about this and look forward to keeping you right up to date about our work and relevant issues. You can now receive Trust Alerts by registering your email address at www.tymestrust.org.

Alerts will be sent approximately once a month and will include news on Trust activities and advice or information we think you should know. There will be no advertising and you will only receive emails from us; your email address will not be given to anyone else.

How do I subscribe for the new Alerts emails?

- 1) Go to www.tymestrust.org and look for the Trust Alerts Emails box.
- 2) Type in your email address, select *subscribe* and click *Do It Now!*
- 3) You will then be sent a confirmation email.
- 4) Click on the link in the confirmation email to confirm that you want to join the service. This is so that only you can add your email address.
- 5) That's it - when the next Alert is sent, you'll get it!

What does it cost me?

Technically nothing, but we would appreciate a yearly donation. We are not suggesting a particular amount as

we leave that to you. We all know of families who are struggling financially because of the need to stay home taking care of their sick children instead of being at work, and we feel it would be wrong to exclude you on the grounds of ability to pay. You can donate securely online at our website via credit or debit card or PayPal, or you can post us a cheque.

We do ask everyone to please remember that the Trust has genuine need of regular funds to provide Vision and all other services. It is the donations we receive from our members that keep things running. We have no government grants as we keep ourselves independent. So we rely on you, just as you rely on us.

Together we can change the world, bit by bit.

Can I reply to an Alert?

Not directly. If you want to respond in any way, use the Contact Us form on the website as usual, or telephone our Advice Line on 0845 003 9002. Giving us your telephone number speeds our response to you.

Come and meet us in North Wales

On Friday 16 May 2008, in ME Awareness Week, you can meet Keith Harley and Jane Colby at the Trust's Clywd Partner Group Annual Conference.

Jane's talk details the links between ME and polio, a disabling illness that hit children in the 20th century.

People thought polio had been beaten but Jane will have new information from John Chia MD, the Californian virologist whose work has revealed enteroviruses in the stomach. Antivirals may offer a cure for ME.

Will your teacher be trained by the Trust?

On Wednesday 16 July 2008, Jane Colby is running a teacher training event in East Sussex on best practice with ME pupils.

Could your teacher join in? Suitable for all teachers, home tutors, Special Educational Needs Coordinators (SENCOs), Connexions staff, Educational Psychologists and anyone concerned with education.

Social workers and medical professionals are also welcome. Some parents may also be admitted, numbers permitting.

New ME group for young people in Billericay

If you live in or around Billericay, Essex, you may want to join a new local group especially set up for young people with support from The Young ME Sufferers Trust. Called 'MenU', the Group approached the Trust for advice about the needs of young people with ME.

Jane Colby attended the inaugural meeting and is looking forward to visiting the Group at one of its drop-in sessions. Contact details are available from the Trust.

House of Lords : Learning Commitment Awards Trustcard service expands to include Colleges

The Queen's cousin Lady Elizabeth Anson, Friends' patron of the Trust, presented the first online Learning Commitment Awards on behalf of the Trust and the Nisai Virtual Academy.

A House of Lords reception and celebration was hosted by Trust Patron Earl Howe and addressed by Lord Adonis (Parliamentary Under-Secretary of State for Schools) and Shirley Conran OBE, best selling author and long term ME-sufferer.

Pupils with ME/CFS achieve GCSE and AS levels above those of healthy children through the interactive virtual courses provided by the NVA in partnership with the Trust.

One student wrote: 'I quickly found out that this is the best way for someone who is not able to attend school or college to have an education. It also has the advantage of giving some contact with the other students and teachers. This is very important, as most people with ME have little or no social life.'

'As my first maths exam result (95%) showed, e-learning does work well. By the end of the year, I had AS-levels in Maths (grade A) and ICT (grade B). Then, as if things couldn't get better, earlier this month I received the result for the maths exam that I took this January. I got 100%'

Lord Adonis launched the expanded Trustcard service: 'In government we find that partnership is often the best way forward.' The card is endorsed by the Association of School and College Leaders. 'An excellent idea - and so simple,' said Lord Adonis, presenting the first card to 12-year-old Shannen Dabson, who was in her wheelchair.

The Young ME Sufferers Trustcard
www.tymestrust.org/pdfs/trustcardinfo.pdf

Nisai Virtual Academy
www.nisai.com/NVA/index.htm

Reminder - your GP's recommendation is enough to start home-based education

Local Education Authorities typically (and wrongly) avoid providing education in the home despite a GP's recommendation. This is because the example of a Local Education Authority policy (Havering) chosen for inclusion in the statutory guidance *Access to Education for Children and Young People with Medical Needs* cuts the GP out of the loop.

When *Access to Education...* was published, we had a meeting with the then Parliamentary Under-Secretary of State Baroness Ashton. We drew her attention to potentially serious problems with that document which would lead to misunderstandings in LEA policies unless they were clarified. No clarification was issued at that time, so the problems occurred and are still occurring.

For a simple analysis of these misunderstandings, see *Professional Guides - Back to School?* at www.tymestrust.org. You can use it with GPs and schools in order to obtain your child's legal entitlements.

The Guide analyses how relapses in children with ME are being caused by inappropriate programmes of reintegration arrived at through misinterpretations of the statutory guidance *Access to Education...* and was first published in *Special Children* magazine April/May 2003.

Lord Adonis, the present Parliamentary Under-Secretary of State for Schools, met with us and in 2006 issued a letter explaining that a consultant's report is not needed before educational support is provided in the home. As we pointed out, this would contravene the statutory 15 days by which a child absent from school through illness must receive other provision.

Quotes from Lord Adonis' statement are on page 5 of *Vision 2006-2* at www.tymestrust.org.

Did you know?

In 1997, the *Journal of Chronic Fatigue Syndrome* published the largest ever study of ME/CFS. Carried out by Jane Colby with Dr Elizabeth Dowsett on a UK school roll of over a third of a million children, ME/CFS was found to be the biggest cause of long term sickness absence - at 51%, more than double the rate of cancer and leukaemia combined. The study is referenced in the Department of Health Report of 2002 (see www.tymestrust.org/pdfs/keypoints.pdf).

The Colby Report

wants your contribution

Dr Elizabeth Dowsett always told me that those who don't have hands-on contact with patients get out of touch.

Similarly, I think that those who write about ME need to include first-hand knowledge gained from patients. If the writer has also had severe ME themselves, as I have, that helps to authenticate the work. But I am disappointed at how often sensible professionals, in regular contact with patients, don't seem to listen to what they are being told, or somehow filter it through preconceptions rather than being prepared to learn something new. Those who do listen are like gold dust.

In The Colby Report I am incorporating contributions from patients and families. I hope you'll be pleased to hear that the core of my 1996 book ME - The New Plague (out of print but regularly in demand) will be there too, revised with new information on potential diagnosis and treatment.

Concise but unusual questionnaires are available for you to complete, and space has also been allocated for some personal stories. This is your opportunity.

Jane Colby

I have worked for the NHS for over 30 years before becoming a full time carer for my daughter, who is now 16 years old. I was firstly a registered Nurse then a Midwife. I, like most people who have never experienced ME, thought it was a convenient condition, for those who chose to malingering.

Kate started at the age of 11 with tonsillitis. It took almost 9 months of constant ill health for her to have her tonsils removed (I had to pay, I might add). She had a set back when five days after that she had a rip roaring infection with extremely high temperatures. I was assured by one and all that now her tonsils were gone we would not look back. How wrong they were. She has never been well since.

For the following 2 years, as her health never improved, she had several diagnoses. Post operative fatigue was the first, then post viral syndrome. 'Growing pains' was one doctor's answer to the pain she felt. There were times when she would appear to have 'outgrown' her ill health, followed by crashing lows when she was ill again.

My intuition told me, 24 hours a day, 7 days a week, that something was wrong with my child. Because I had a nursing background I was charged with 'having a little knowledge, that was dangerous'. No-one openly said this, it was always couched in friendly banter.

In reports, I was accused of overly identifying with my daughter, and not allowing her to develop. Reports alluded to, but never actually accused me of, Munchausen's by Proxy. I was charged with having a little dangerous knowledge, yet treated like an imbecile. Did they think I was so stupid that I would not recognise what they were implying. Yet I knew she was 'not right'.

As a Midwife, how many times I have seen a mum-to-be come for monitoring

because something is 'not quite right', only to find she was correct in her assessment, something was wrong. There are mothers out there telling people something is amiss, and being dismissed for their lack of knowledge. They are labelled as over anxious parents.

Intuition, the dictionary definition: 'instinctive knowledge: the state of being aware of, or knowing something without having to discover or perceive it, or the ability to do this.' Most mothers appear to have this ability, yet very few people appear to recognise it. What is worse, this ability is most often dismissed. I understood all about intuition. I had seen it in action many times. Now it was my turn.

All this stress took its toll. Self doubt set in, my self-esteem plummeted. Throughout all this, professionals frequently highlighted our 'unhealthy dependence on one another' and once again, 24 hours a day 7 days a week, my intuition told me that something was wrong with my child. I was advised to try and make her more independent. Not to run after her all the time. To 'push her more'.

By her 15th birthday she decided she would fight this. I bought her an exercise bike and a treadmill. With every mile she ran or biked, she became more and more exhausted. If people gained more stamina through exercise, where was hers? And why did her muscles never stop aching like most people's do?

In March 2007, someone listened and took on board all I was saying. She asked if anyone had ever diagnosed Kate with ME and I replied confidently 'No, she does not have that'. She recommended I look at the Tymes Trust website. That was the day I had my epiphany.

That one defining moment. I

remembered Kate saying ‘Mum, have you ever not been able to swallow?’ and there before my very eyes, not only all the aches pains etc, but the inability to swallow. I believe her problems started in September 2002 with the onset of those high temperatures. Yet it was April 2007 before she was diagnosed with ME.

It is not a diagnosis to leap up and down with joy at. I have been reassured, ‘That is not life threatening’. Kate

disagrees. She reckons that ‘no-one can call it life.’ But it has led us both to another journey. More battles to fight. I am still treated like an idiot by the unbelievers, but I battle on.

Elaine Charles RGN; RM

Kate and Elaine’s story appears in full in The Colby Report

Your Question

***My husband Jon, who has ME, has been put forward for a psychotherapy scheme. CBT and Graded Activity is advocated. The therapist was positive when Jon mentioned ‘pacing’ as the best approach; however, he follows the standard method for these therapies. What can we expect?
Jo-Anna Roberts***

Jo-Anna,
Cognitive Behaviour Therapy (CBT) and Graded Activity (GA) - the new name for Graded Exercise Therapy (GET) - seem to mean different things to different therapists. Some use these names for a management programme that is actually more like ‘pacing’, where you tailor what you do to your body’s reaction - if symptoms get worse, you adapt the programme accordingly.

NICE, however, recommends that CBT be carried out under the principles of Graded Exercise, based on the theory of ‘deconditioning’. This theory says that patients are unable to do things because they have become ‘deconditioned’ (ie unfit) through not being active. Patients are thought to have developed an activity avoidance behaviour due to fear of provoking symptoms, so the programme aims to get them moving again. The therapist reassures them that no harm will come to them and that the activity programme should be adhered to.

Therapists initially try to establish what they call a ‘baseline’ - a level of activity that the patient can tolerate day after day, regularly (which in itself doesn’t allow for the characteristic variability of classic ME).

From then on, activity is regularly increased, though usually quite slowly, and the programme must be continued as prescribed, even if symptoms increase. A professor in this field was put on the spot by being asked in a lecture if this could cause harm and denied that it would. That does not accord with the experience of many patients in large patient surveys.

We would always advise people to use their own judgement about accepting therapy, and about how therapy is affecting them, rather than uncritically handing control of their lives (clock-watching or egg-timer monitoring, for example) to someone else. That person may not necessarily understand classic, neurological ME.

It’s worth remembering that exercise-induced exacerbation of symptoms is one of the key diagnostic criteria for classic ME. It is also a key feature in the Canadian criteria of 2004. These were the first clinical diagnostic criteria for ME/CFS, which the Trust was first to endorse in the UK. People with ME get worse if they exercise. By definition.

So, if classic Graded Exercise/Activity helps you, it must mean *either* that your form of chronic fatigue is not the classic neurological ME as described by Ramsay, or else your body *has physically already recovered* sufficiently to withstand the increases in effort - even if you hadn’t yet realised it. These are the only logical explanations for standard Graded Activity helping people with ME/CFS.

Letting you stop if your symptoms get worse is not standard GET/GA - it’s pacing.

Jane

Read ‘The Good, the Bad and the Ugly’ in Vision 2007-2, covering the NICE Guidance on CFS/ME. The ‘Good’ section quotes helpful recommendations on how patients should be treated. The ‘Bad’ and ‘Ugly’ sections are self-explanatory.

We hear that some ME Clinic staff seem to think that a programme of graded activity should fix things, and when it doesn't, patients are made to feel that this is in some way their own fault.

In August 2007 the National Institute for Clinical Excellence published its guidance for doctors on CFS/ME, entitled *Chronic fatigue syndrome / myalgic encephalomyelitis (or encephalopathy) : diagnosis and management of CFS/ME in*

adults and children. Many clinics do not provide what young people with ME, a neurological disease, want and need, but this is hardly surprising, because they are primarily following the NICE Guidance. What are professionals supposed to think?

At a north of England conference where I spoke on education, a speaker from the local clinic assured the audience that everyone with ME could walk to the top of a mountain - they just had to go slower than others!

In 2005 when ME Clinics were first mooted, the Trust applied for a grant from the Essex Community Foundation Local Network Fund to consult with its young Essex members and produce a report on their needs and what they required from a clinic.

In consultation with Dr Nigel Hunt, General Practitioner and Associate Director of Post Graduate GP Education, Eastern Deanery, a questionnaire was designed and completed by forty-eight young people and parents in Essex, who gave detailed descriptions of their lives and the difficulties they were facing at the time or had faced in the past. Some also gave telephone interviews. Five families in other

areas completed the same questionnaire for comparison purposes and told a similar story. Our Focus Group gave careful consideration to the key issues of how clinics could support the education of young people with ME, and help them to be believed and taken seriously, while 111 other members completed a simpler questionnaire and supplied extra information. This established that the

Essex experiences and views were consistent with other areas. Overwhelmingly, our respondents wanted practical help. All patients have the right to have their needs respected and for the management of their illness to be tailored to those needs. This is why we think that this report about young people's needs could help you explain how your own needs might best be met.

Patient Choice

A key finding was that 96% of respondents would like a choice of which professional co-ordinated their care. No-one said that they didn't want any choice in the matter, yet we have families who are being made to feel that their care must be overseen by a particular doctor or clinic.

Over half of those who wanted a choice, wished for their own GP to co-ordinate their care, and not a CFS/ME clinic. Where this is their wish, we believe it should be

respected, rather than a particular doctor or team being imposed upon the family because it is regarded as the specialist service for that area.

Some Positive Experiences

'My paediatrician has been supportive.'

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

'My GP was very understanding about my condition. He wrote a very helpful letter to help me get

home tuition. The paediatrician did every test to rule out any other medical condition.'

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

Some Negative Experiences

'They were unbelieving, looking for mental reasons'

'The paediatrician was hugely critical of everything we were doing initially, including using

"Our Needs Our Lives"

our report revisited

a wheelchair. My daughter is continuing to recover, but not from any support from any doctors or health professionals.'

'They refused to supply home visits or care. They told me to pull myself together. They were very rude and hostile and wrote letters talking about me having "fixed ideas"'

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

Some experiences were mixed

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

We asked what might have helped but was not provided

'An understanding doctor.'

'Early diagnosis.'

'More support in the early stages.'

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

'Being believed.'

'Acceptance that she needed a wheelchair.'

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

'A disability badge.'

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

'Understanding that sensitivity to prescribed medication may occur.'

'A letter to say that our son was unfit for school.'

'No insistence on school visits when she was still severely affected.'

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

'Home visits.'

'Respite care or help in my home.'

'Being able to take exams at home.'

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

'The clinic could give out information about the Trust.'

'The new clinic should support the Tymes Trustcard¹.'

What should a clinic provide?

92% wanted a helpline

67% wanted domiciliary visits

79% wanted support for carers

75% wanted afternoon appointments

92% did not want automatic involvement of psychologists or psychiatrists

What makes ME worse?

88% circled exercise

79% circled going out

71% circled school or college attendance

67% circled school work

25% circled immunisations

¹ The Trustcard is a pass card to ensure that students get the support they need at school or college. Endorsed by Lord Adonis, Parliamentary Under-Secretary of State for Schools, and the Association of School and College Leaders. Apply to the Trust.

The full 42-page report: www.tymestrust.org/pdfs/ourneedsourlives.pdf. Presentation copies available.

If you would like to give us feedback in confidence about services in your area, whether about GPs, consultants, clinics or other health professionals, you may write in or use the Contact Us form at www.tymestrust.org or telephone us on 0845 003 9002.

To : Exeter, East, North and Mid Devon CFS/ME Service

Having in the past been more focussed on adult services, I haven't come across this document before, nor forwarded it when you were first setting up the service. Nevertheless, it seems a valuable document: "Our Needs, Our Lives; What young people with ME require from a CFS/ME clinic". It is a survey report prepared in 2005 by The Young ME Sufferers Trust.

My focus has changed recently and I have been extending my reading, encompassing this and the other excellent publications for professionals available free at www.tymestrust.org/tymespublications.htm. Some of these are particularly helpful regarding education for young people with ME. Of course, you've very possibly already accessed these.

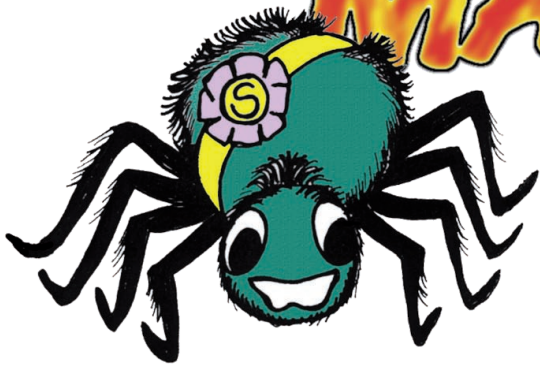
The attached survey, however, I thought was particularly useful in

presenting the patient/service-user perspective and there are very clear themes running right through, which I felt obliged given my patient/service-user representative role on the CFS/ME service steering group to present to you. I trust you will give them your attention soonest.

With best wishes,

Jacqui Footman
Information and Publicity Officer
South Molton ME Support Group

SEB'S MANOR



Did you see on Nisai's website that I got into the Virtual Academy???

Sebastian Says

Hi again everyone! Chloe's taken over my Art Spot again with her Dragon and she's also drawn Nanka, a big-headed Husky. (As if I could choose which to print! I'm printing both.) Come on you guys, more artwork please...

Of course, someone like me can't imagine what it's like to be big-headed. When you're so clever you don't need to boast. You just know you're the best.

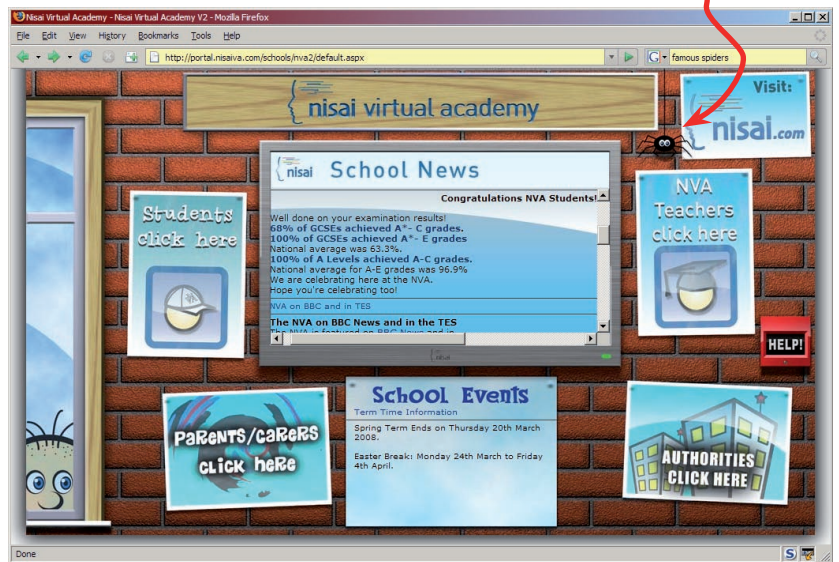
I'm also very soft-hearted. Sally Buck's kind letter made me cry. She offered to let someone else have her copy of *Vision*: 'I still want to be a member but just thought that someone poorer than me might need the magazine to help them and their family, cuz I know it costs a lot to make and send to all the children with ME.'

Thank you Sally. Don't worry, we'll manage to send yours too. What's this? Ah, the all-important PS!

'I forgot to say a big thank you for my prizes. The gloves fit perfectly and I am so going to enjoy reading the *Young Hearts* poetry book with my mum and dad.'

As you all know, I'm in charge of the prizes and I chose the furry gloves specially for Sally.

Now, what can I choose for you?



Hello, my name is Eloisa Longley. I'm 12 years old and I've coloured in the winter picture. Thank

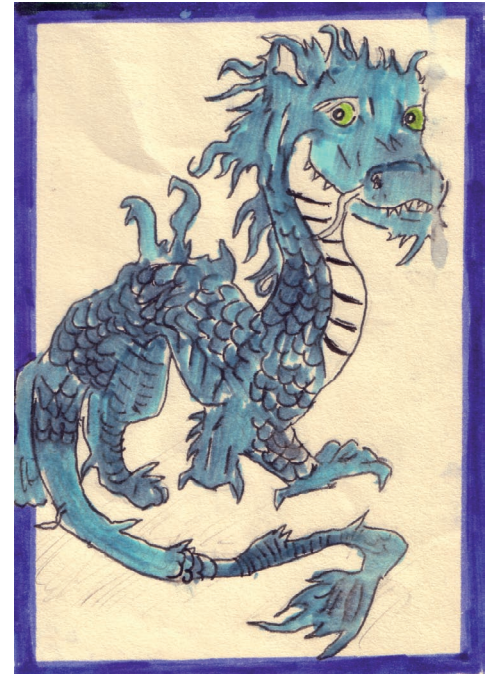
you for making me smile reading *Vision* and *MiniVision*. I can't wait for the next one to come in the post! And thank you for all the help you've given me.





Dear all at Tymes Trust and Seb

I'm feeling arty so I drew you a picture of Nanka. He's one of the characters in my new story about Huskies. He's the eldest puppy in the litter and he's very big-headed and full of himself. But the dragon is my artwork for Seb's Manor.



PS I love *Vision*. I was thrilled to see my last Huskie picture printed. Thank you soooo much.

PPS I love Seb and he is the nicest spider I have ever had the pleasure to meet.

Chloe Halstead



I make jewellery, when my hands allow, and I thought I could maybe send you some



things I have made to go in Seb's Treasure Chest or to just give out to people?

Indra Wignall

Thanks, Indra. If you'd like some of Indra's jewellery, just write me a nice letter or poem or draw me a picture. (Tell me if you have pierced ears...)



Sally won a prize in January for the correct answer to *My Room* (Things 4 U 2 Do, *Vision* 2007-2). Indra Wignall won a prize for it in April! We don't mind if it takes you a long time.



It took me

ages to do this because I just had my tonsils out and feel quite poorly. I'm going to be 14 in a couple of weeks.

Sally Buck

I think I should unsubscribe from *Vision*; I am about to turn 26. I am still rather ill (disabled even) and naturally I will miss Seb. Tell him it wasn't him - it's me - I'm moving on but will always think fondly *SNIFF* etc. I wish I could tell you the secret cure that allowed me to progress from 20+ hours a day in bed to 14 hours a day out of bed, 4 of which are spent at work, but really I think it was just time. And pacing. And chocolate (ok that one is wishful thinking).

Kindest regards and warmest wishes, Mary X

Oh Mary I'll miss you too! Of course, you could become a Friend, or a 26 plusser?

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



ALAN THE ALIEN CONTEMPLATES LIFE, THE UNIVERSE AND EVERYTHING

I'm Alan the Alien, I am, I am
(I like my cucumbers pickled in jam)
When I'm exhausted I crash out on Mars
(I like my jam in boxes not jars).
So where do you like to go for a treat?
When you're well enough, what do you eat?
How will you spend your summer this year?
Send me an email and bend my ear.
PS I don't have any ears.
PPS Then again, I haven't looked lately.
Prizes for the most spaced-out answers.

A poem from...

Belief means different things to different people. We were touched by this life-affirming poem from Robin Sansom, whose other poems you will find in Young Hearts.

THE LIE | **ROBIN SANSOM**

Fear was plaguing me in an alley of my doubt,
Dark shadows of unknown creeping in and out,
A mirror on the wall laughed and said its lie,
'Look at you, you're nothing, kiss your dreams
goodbye.'

Deep into my soul cut the sharpened blade,
The sorrows of my past, a wound that was made,
A serpent on the floor hissed and said its lie,
'Look at you, you're broken, your river has run dry.'

Falling in this pain, as I struggled on the slope,
The weight on my back, pulled against my hope,

The mountain in my life loomed and said its lie,
'You will never make it, the climb is too high.'

Weak on my knees, a cry was on my breath,
The battle in my heart, a fight to the death,
A voice in the wind chilled and said its lie,
But something from within me rose up to defy.

Breaking through the chains in the prison of my
head,

A prayer from the heart, no word that was dead,
A voice in the night, brighter than the sun,
The truth of my saviour, came to overcome.

SILENT VOICE FIVE YEARS ON | **JADE SMITH 18**

Perhaps someone will listen
I don't care whom,
As long as they get it right
The feeling inside of me
That's important to me.
They keep on pushing me
Don't listen to me,
What's happening to me.

How goals relapse me
They don't understand ME
But say they do.
Why don't they care
and learn.

Perhaps someone will listen
I don't care whom,
As long as they get it right for me

This terrible thing
That's taken over me.
My trust is there for those who care
They sit and talk about me.

Some not seeing me for a while
Others don't know this young person.
Hope they think about this for a while
Remember I am a young person with a VOICE.

My life has not changed for so long
They say I am adult
Parents can't help me anymore.
I am not the age they say I am,

Been too ill to get to that age
I know I trust my parents
and they will fight for me.
Their faces show they care
and they will do their best for me.

Professionals feel they know what I want
or is it what they want?
As adult I have the right
To say what I want and who I want
to speak for me
and look after me.
If that is my legal right
Professionals say I should be shown how to trust
Trust is what you earn
Not just handed to you.

Need help through my day
and help with my memory.
People don't understand this
feel they know best.
But they don't they have any idea
what this illness is like.
Till they live this illness
They can't say what we feel
They have no idea what pain we suffer
How we make it through our day
and what our day entails.

Our illness is real.
Please take note.

Love to Jade and all our severe sufferers. We do think of you. Perhaps your parents can send us news of you and a photo if you can bear the flash.



Fudge

Hello! Does any one remember Fudge the Bear ?

She was sent to me from the Trust a few years ago and found fame on your website! and has also featured in the magazine when she went on holiday to Paris.

Well I have been keeping busy on many a low energy day sewing little outfits for her, and I thought you may like to see some of them. I still have some more ideas for designing more outfits for her, it stops me getting too bored when I haven't got a lot of energy which is most days



My experience is that sleeping during the day (at least until 12 noon) is the best and healthiest time (for me) to sleep. If I force myself to stay awake in a normal day/night cycle I become much more ill with sore throats/glands etc. If I wake up before 10-11am, I am very shaky and nauseous (to the point of vomiting).

I did force myself into a normal day and night pattern for years

Today is my college day so I am very worn out.

although I have a little more energy on a morning, and once a week I am attending a ceramics course for a short time which I enjoy very much even though it wears me out and I need to rest for two days afterwards.

Hope you enjoy the pictures and a Happy Easter to all

Love Cheryl Neyt and Fudge x
PS Hope Seb's OK - hope he isn't jealous because I haven't made him an outfit but I think it would be a little hard with all those legs...

Of course we remember Fudge. And Seb is fine about this. Very magnanimous. He quite understands.

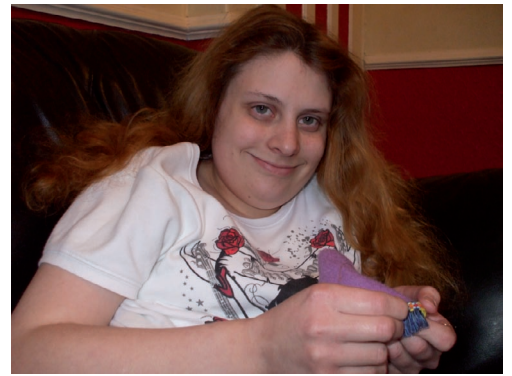


A pot I made and glazed at college

Jeeves! Come here. I can't lift the remote.

and it did me no good at all. The symptoms didn't get any better. I was 'well enough' to spend years working like this but it was very unpleasant and I made a lot of mistakes. I also kept vomiting at work and falling off my chair.

Now, I sleep from roughly 12 midnight to 12 noon, I feel better during the time I am awake and have less ME symptoms. I sometimes have a period in



We'd love to have photos of all the other bears we've sent out over the years! The Bobby Bears, the Beefeater Bears, the Le Blanc Bears, the Big Apple Bears... Where are they all now? Have they got degrees from the Open University? Let us know.

Time for bed?

the evening when I feel almost normal and have some energy. This never happens if I change my sleep pattern back to night-time sleeping.

Annette Barclay

Many people with ME share Annette's experience that sleeping at unusual hours may be helpful to them. Let us know your experiences.

At Home With The Trust

Our first virtual At Home!



Instead of an Open Day this summer, The Young ME Sufferers Trust and Nisai Education invite you to an online event: 'At Home With The Trust' on Tuesday 1st July 2008, 11:00am to 11:45am. You can leave early or maybe stay on for a while...

Join us wherever you live for this special online event - all you need is internet access. It's the first in a series of free 'webinars' for our

members, friends, teachers, medical professionals - anyone who's interested. Watch a short, online presentation about ME from Trust Executive Director and former headteacher Jane Colby. Then have the chance to ask her your own questions.

Booking is essential. To book your place now, email info@nisai.com or use the contact form at www.tymestrust.org. Booking closes Friday 20th June! For more information telephone 020 8424 8475.

Simon at Nisai says: 'We are hosting this webinar completely free of charge but we do ask participants to kindly make a donation to The Young ME Sufferers Trust, which can be done securely online at www.tymestrust.org.'

Precious Petzzz!

Do you like puppies? Two of the best prezzies we have ever had to offer have been given to us by kind Simon Selkin. We can confirm that they are extremely well behaved, and although they like to sleep most of the time, they don't snore (much). They get all their own meals and groom themselves when you are asleep.

Invent a name and write to us about how they might fit into your home. We'll print your entries and put your names into a hat for the puppies! We have a boxful of other goodies for the runners up.



FACT

Far more females than males suffer with ME, and most young people with ME are in their teens. But we like to hear from all of you! We're just an email away - contact us in confidence at www.tymestrust.org.

Alert - Education Rights

The Trust is regrettably seeing an increase in school attendance being used as a sort of 'graded activity' programme with little regard for children's educational rights, achievement or success. We are having to advise many families on the action they can take. Once again, more parents are also telling us about suspicions of their parenting from various children's services. Contact us if this affects you. Sign up to the Trust's new online Alerts system - see page 14.

Trust Alerts Emails

subscribe | unsubscribe

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