

The Young ME Sufferers Trust

2007-2

£3-95

Vision

for young people, families and professionals



HOUSE OF LORDS

Trust and Friends celebrate
Virtual Education success

NICE REPORT

The Good, the Bad and the Ugly

NEW RESEARCH

Enterovirus link confirmed

THE BRIEF

Activity programmes may be harmful
Independence of charities threatened
What is Pervasive Refusal Syndrome?

View in full colour at www.tymestrust.org



What's Inside

Vision - The Project	3
Learning Against The Odds	4
What You Think	6
What Have You Been Doing?	8
Remember The Children	10
Meet The Team	11
Things 4 U 2 Do	12
<i>Centre Pullout</i> The Brief	i-iv
Yvette Cooper MP	14
Enterovirus Link Confirmed	16
Is ME Now Classified As CFS?	16
NICE - The CFS/ME Guideline	18
Seb's Manor	20
A Letter From ...	22
Young Hearts Sky Dive	24

THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

Founder Patron	Lord Clement-Jones CBE
Patrons	Earl Howe Barbara Windsor MBE Shirley Conran OBE Terry Waite CBE The Countess of Mar
Friends Patron	Lady Elizabeth Anson
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Our data protection policy is available

Cover : 'You can't have a virus. You ARE a virus.'

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



We have just come of age. In June we turned 18 years old - so we can now vote!

I have been talking to our Executive Director Jane Colby about our history as the longest running support organisation for children and young people with ME - we recalled how the Trust became a national charity in 2000 as a result of escalating demand for our services, and how we decided to

News Extra

Speaking of voting; unfortunately, no-one got to elect the membership of the National Institute of Clinical Excellence committee which wrote the draft guideline on CFS/ME that caused such concern earlier this year. We submitted our concerns in detail (see *Vision 2007-1*). NICE was to have published their guideline in April, but as a result of our response, and those of others, publication was postponed. It is now published at www.nice.org.uk/CG53.

Our evaluation of their final publication is on pages 18-19. The 'patient version' of the NICE guideline on CFS/ME (called *Understanding NICE Guidance*) is available in hard copy free of charge from the NHS Response Line on 0870 1555 455. You must quote the NICE document reference number 1303 when calling. NICE also prints hard copies of the *Quick Reference Guide* - a summary of the recommendations for health professionals (ref 1302).

change to our full name - The Young ME Sufferers Trust - to make our role crystal clear.

It is quite amazing how much has been achieved, including our role on the Chief Medical Officer's Working Group. Since 2004 we have been in partnership with the Nisai Virtual Academy which provides interactive virtual education, and earlier this year we celebrated the success of our young members at the House of Lords. We were honoured that this event was attended by our many eminent patrons and by Lord Adonis, Parliamentary Under-Secretary of State for Schools, who addressed the guests in glowing terms (see overleaf).

Our website is a regular resource for families and professionals alike, chosen for national archiving by the Wellcome Trust. You'll find free publications there for you, your schools and doctors; many carry the authority of having been published in professional journals.

Yet the Trust is still significantly different from other national ME organisations. Jane explains: 'People often think that the Trust is a big organisation with state funding because we do things professionally. In practice we remain totally voluntary - a close-knit and dedicated team with members throughout the UK, who donate their time to make it all happen day by day, week by week, month by month.'

Our funding is almost all by donation from members and well-wishers. We were interested to read The Centre for Policy studies' criticism of state funding for large charities, who may then need to follow an 'official' line - acting, in effect, as another arm of the state. In the Centre's report, they flag up the



Keith Harley

danger of charities losing their independence by becoming detached from their voluntary donor base and they also criticise the substantial salaries paid to staff. You can read more on that in *The Brief*.

We prioritise a personal, hands-on approach. Jennie, a Trustee and Trust Secretary also gives one day a week to 'Children's Day' when she and Jane work together to ensure your letters are personally attended to.

Being Executive Director means that Jane not only directs the organisation but, as she terms it, 'gets stuck into' the work itself.



As Dr Betty Dowsett says, 'People who don't remain hands-on get out of touch'. As the Chair, I'm afraid

I'm not allowed to just sit back either!

Kind regards

Keith Harley
Chair of Trustees

New Phone Number

0845 003 9002

The Trust has updated its telephone system. Our voicemail is constantly monitored so always leave a message if we're busy.

We look forward to helping.



There is nothing like tea on the terrace of the House of Lords to put you in a good mood, so it was not at all surprising that the guests assembling for the Tymes Trust's Tea reception should have radiated such an air of collective cheerfulness.

Needless to say, we were in the House of Lords not just to enjoy the sumptuous sandwiches and scones but also to celebrate something special - the Trust's 'Virtual Academy' partnership which has enabled children with ME to pursue their educational studies from home - and

to do so with staggering success.

Tim Clement-Jones, the Founder Patron of the Trust, was sad to be absent because of a debate in the House of Lords, so it fell to me to deputise for him and to introduce the afternoon's speakers. Jane Colby told us movingly about her own experience as an ME sufferer and reminded us of how the Virtual Academy link began just three years ago. She paid tribute to Dhruv Patel and Andy McGarry from Nisai Education, whose partnership with the Trust has provided a real lifeline to many young people.

Jane was followed by our special guest of the afternoon, Lord Adonis, who took time out from his busy schedule as Schools Minister to launch the second generation Tymes Trustcard - a very useful pass card for children with ME in school. Our Young Advocate Shannen Dabson, aged 12, was presented with her card by Lord Adonis, who congratulated the Trust on this excellent initiative.

The afternoon concluded with the most impressive part of all - the

Learning Commitment Awards, which recognise dedication to learning in the face of illness. The winning pupils (Lorna, Ben, Caroline and Richard), whose pictures and achievements were projected onto a screen, had their citations read out, and despite their absence all were deservedly applauded at the end.

After that there was still time for guests to polish off the tea and to meet some of the staunch supporters of the Trust such as Lady Elizabeth Anson and Shirley Conran, two of our Patrons. Well done to Jane Colby and the Tymes team for giving us an afternoon to remember!

**Earl Howe, Patron
The Young ME Sufferers Trust**



Schools Minister Lord Adonis praised the Trust and its partnership with Nisai Education. Head of Nisai, Dhruv Patel (below with Earl Howe) and Andy McGarry (below right) described how the Virtual Academy works and why it was created.



As Founder Patron of the Trust, I am extremely proud of its success in promoting virtual education for children with ME, through partnership with the Nisai Virtual Academy.

Circumstances prevented me from addressing the guests myself, so I thank Freddie Howe for magnificently stepping into the breach with his customary skill and warmth. What a

wonderful day for everyone concerned.

**Lord Clement-Jones CBE
Founder Patron**



Learning Against the Odds

reception and presentation in the house of lords

Earl Howe and Jane meet Burn Gorman (Torchwood, Bleak House), wife Sarah...



Gordon Radley (Sky TV) with Jane



...and Sam



From left: Dhruv Patel (Nisai); Keith Harley, Jane Colby, Mark Colby, Saj Pervez (the Trust); Chris Shaw (Pink Elephant)



From left: Lady Elizabeth Anson, Jane Colby and Shirley Conran



He'll be impossible after this...



Sir John and Lady Carter

'To go onto the terrace on such a beautiful day was a treat ...'
Catriona Courtier
Friend of the Trust
(full letter page 22)



Shannen Dabson and father David

Quick! Grab the scone while she's not looking



They really do provide exceedingly good cakes...

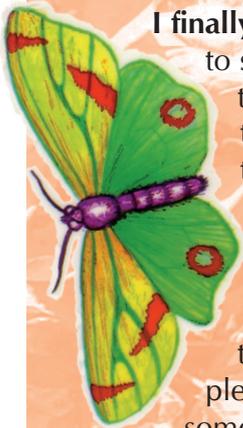


Dr Charles Shepherd (MEA) and Sally Crowe (PRIME)



Photography : Pink Elephant, Fatima Celestino, Mark Colby

what you think



I finally got a chance to start to read through *Vision* today - one of the best, I must say! So much useful info and a good dose of fun too. By the way, could I please request

some butterfly window clings if you have some left? They would look great on our skylights. I love butterflies - they are a special symbol for me. I was in a library the other day for the first time (properly) in years and I spotted 'The Hungry Caterpillar' - I read through it and it made me smile so much! I was with my dad and showed it to him - it made him laugh too! He said he'd read it to me so many times! (You can print that story if you like!)
Jo-Anna Roberts



So we did. We've just a few butterflies left if anyone would like them?

Many thanks for the two copies of *School Examinations and ME*. I did speak with your Exams Officer back in February/March - what a pleasant and helpful gentleman - wish there were more like him in Education. With his advice I have been able to organise Eleanor's exams to be taken at home - after months of seeking advice from all the usual sources



I have heard rumours that Elvis is in fact alive and well and a member of the 26+ Group - are you sworn to secrecy on this matter?

Best
Matthew Ecclestone

No - he is.

Just dropping you a line to say thank you for the recent copy of the magazine, it's arrived just in time, I'm in the middle of a huge low at the moment, it's always nice to get your magazine, but this week was extra nice. When you are trapped in bed for days on end it's often nice to know that you aren't on your own, this illness can be such an isolating one, and it's always nice to know im NOT on my own and there are other people that understand how this feels.

Indra Wignall

without success! Thank you to you and all the wonderful staff at the Trust. The enclosed is a small contribution to the good works you do. Many many thanks. Keep well. Kindest regards, Sherry and Eleanor Brown

In the event Eleanor wasn't quite well enough to do her exams and is taking a break from education. We wish her well.

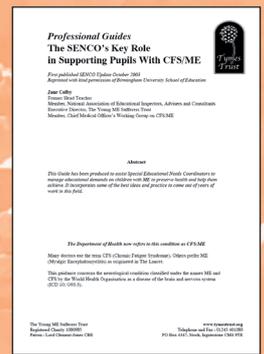


The first thing I do when any parents contact us is to

recommend them to your website. The publications section is so useful.

We have a girl with ME in our group, in Year 9. I went with her parents to a meeting at her school a good few months back. Her mother was very clear about what she wanted for her, just worried that she might encounter resistance but all has been well and there have been great improvements in the girl's health. It was quite strange because the meeting was at the school where I used to teach and the school did all sorts to try and get the parents to go in on their own and not take me with them, but they just got more determined. They tried to say that home tuition was very difficult to come by and how difficult it was to get through the LEA, but we gently kept on about the entitlement, took a copy of Megan's story and lots of the stuff from your website. It was amazing how quickly home tuition was arranged in the end and how well it has gone. The school were very grateful for the SENCO information we printed out from your website.

Jacqui Footman



Friendship

Our 'missing rhymes' poem in the last *Things 4 U 2 Do* sparked off lots of entries and letters on the subject of friends. Here's the poem with the gaps filled in:

*It's when you're sick and can't go [out]
You learn what friendship's all about*

*I try my best to keep in touch
But often can't do very [much]*

*A friend is one who'll be there still
No matter if I'm well or [ill]*

*If I am feeling all alone
Good friends will visit, text or [phone]*

*I'd rather have one real true [friend]
Than many more who just pretend*

Well done to all our prizewinners. Why not try the new missing rhymes poem on page 13?

I'm reading a book called *Friendship according to Humphrey* and I thought you might like these quotes:



*Tell me your friends and
I'll tell you who you are*
Assyrian proverb

*Little friends may prove
to be great friends*
Aesop, writer of fables

*The only way to have a
friend is to be one*
Ralph Waldo Emerson,
American poet and
essayist

And one we can all especially relate to:

*Real friendship is shown
in times of trouble;
prosperity is full of friends*
Also by Emerson

Shannen Dabson

The Friendship Poem where you had to find out the missing words (I have done it - please find it attached) made me think about my own friends. One of my friends says I am her best mate but I have been off school for a long time and I have not even heard from her but some of my other friends say I'm their best mate and I know that is true as they always text and phone (not all of them). So anyone who is ill and they read this poem it is like reading your friendship! People who are ill have different friendships than people who are well! (We have more special friendship.)

Michelle Cross
Age 12

Thanks for your magazine. It would be really nice if you could send me some Butterfly clings for my window which I can look at when I wake up. I also think I have found the missing words for the 'Friendship' poem competition, they are: Out, Much, Ill, Phone and Friend. Your magazine is really good and the advice line is really useful for my mum and dad.

Rachel Pygott

And we just love this spoof entry!

*It's when you're sick and can't go on a roundabout
You learn what friendship's all about*

*I try my best to keep in touch
But often can't do very much rollerblading*

*A friend is one who'll be there still
No matter if I'm well or completely mad or ill*

*If I am feeling all alone
Good friends will visit, text or moan.*

*I'd rather have one real true chocolate bar
Than many more who just pretend*

(I speak with experience on the matter ☺)
Helen Brierley

We know what you mean Helen!



When the NICE guideline was published (see page 18) the Western Daily Press asked 16-year-old Trust member Amy Baldwin what she thought about ME. Amy explained that it was a physical illness: 'When I have a bad day I feel very sick and have aches all the time in my arms and legs. It's very restricting.'

The paper explained that since Amy was diagnosed eight years ago, doctors have thought that the aches and pains were psychological, and that 'her parents were over-protective and imagining things'. They also thought Amy was suffering from 'school phobia'. If this happens to you, contact the Trust for help. Amy missed so much schooling because of her illness that her parents decided to educate her at home from the age of 10. Amy has now earned a place at the City of Bath College to study for a media diploma.

Congratulations Amy!

*Picture courtesy of
Western Daily Press*

WHAT HAVE YOU BEEN DOING?

Dear Jane, Jenny and Co (Seb too of course!)

It's Sazza. It's been so long since I was last in touch I can't even remember where I was at back then.

I'm doing really well now, have been living and studying at an adult residential college in Scotland for people 20 and up who missed out on education. I graduate in 22 days time! *Gulp* Made some really cool new friends, had some great experiences ... such as Bonfire Night on Arthur's Seat, Yurt making ... yes really!

Producing

and recording a radio ad for adult learners week. Have been volunteering at a charity for adults and young people with Aspergers and learning to drive (test booked ... double gulp). Was also voted onto the SRC panel as Vice President!

September I return to Scotland for my certification ceremony (if I pass this course ... fingers crossed) before heading to the University of Wales, Swansea to start a BSc in Psychology where I have a conditional offer.

In celebration of my new life I changed my name last year to Anästasia (it's what Mum wanted to call me initially). It's pronounced ana-star-zia. My friends now call me Star!

Hope you're all doing great with the excellent and fun stuff you provide which enhanced my confidence, enabling me to write Access Level essays and present my ideas today.

Love and bounces

Star :) xxx

(Anästasia

Wadden-

Holmes)

Jade, one of our severely ill members, can't write her story for you, so we are printing this poem that she sent us some time ago. Jade wants us to tell you that she has been put through 'graded' exercise/activity programmes over the years which



have sadly not made her better. We have heard similar stories from other members' families.

We also know of formerly severely ill children who are now greatly recovered after declining such treatment. This counteracts assertions that those who remain untreated will not improve, depending of course on individual circumstances. For more on this subject see *The Brief*.

TIME

Time Ticking by
Ticking so slowly,
I don't know why
Haven't walked for two years
Sometimes it makes you cry.
Time means nothing
Don't mean a thing
Just passes you by,
Don't feel older
Just feel the age
When all this began
Don't know why.
It makes you sigh
I am still learning
About this terrible thing
Which has taken over me
Simple things take energy out of me.
Need to be listened to
So people know
How much I can do.
This is vital to me

Mum understands me
Keeps hope inside of me.
When I feel life is mean
She thinks of something small to do
Only take energy That I can use.
I can't understand when you talk fast
Talk slowly is the BEST
So I can take in while I Rest.
Jade



Do you recall our conversation about the potted dandelions in our garden? They are Olga's and Roses' favourite food. Plans for the August collection went so well that instead of just applying for one weekend we had to apply for three, practically all of August! The kids were a bit of a handful

giving plants out to everyone who donated last year, as the little ones did not realise how fragile plants can be! This year we thought of a different idea, and we've raised £300 for the Trust!

Best wishes
Lisa Dabson



WHAT MAKES ME HAPPY?

We have some great prizewinning entries for the Shirley Conran writing competition launched in the last *Vision*. They win Amazon tokens and gifts from the Trust.

Now we are looking for more prizewinners - could you be one? Shirley asks you to write a postcard telling her 'What makes me happy?' You can use the back of a greetings card picture if you don't have a postcard.

My cat makes me happy because he sometimes has mad moments and my rabbit is really friendly so I like stroking her. I like my hamsters because they do funny things on their wheels. Summer makes me really happy because I like being in the sun and wearing nice clothes. I am happy when I am with my friends a lot. My family makes me happy because they do lots of things for me. I am also happy when I read my *Vision*!

Jodie Halliday

what makes me happy?
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 from Jodie

Well, there are lots of things that make me happy:

- Finding I have post
- Going out!
- Paddling/swimming in the sea
- Chips
- A Sunny Day
- My music
- Wearing my lime green flip flops
- Looking good/having a good hair day
- Being able to help people
- Dangly earrings
- Animals, especially tigers and bunnies!
- Making things
- My birthday
- Writing letters to pen pals
- Finally finishing something which has taken ages to do.
- My maths lesson once a week
- Emails and my mobile making that funny noise to say I have a text message
- Rainbows, stars, bubbles and balloons!
- My ME improving and being able to do more!



Visiting

- relatives, going on holiday and seeing new places
 - Having a go on my sister's trampoline
 - A funny book or film
 - Snow!
 - Gluing things
 - Managing to help out in the Oxfam shop
 - Poppadums and mango chutney
 - Seeing my friends
 - Making someone else smile!
 - Thunder storms
 - Mint chocolate
 - Managing to achieve something I thought I wouldn't be able to do
 - And finally - my stripey socks! :-)
- Helen Brierley

We love to hear when you are able to do more, but we never forget that everyone has different limits and they can vary greatly over time. Happiness can be watching a squirrel in the tree outside the window...



This is me when I went skiing. I'm holding the white sparkle bear that the Trust sent me!

You are all special as you have helped me and lots of people and you understand ME.

Lots of Love
 Michelle
 Cross



REMINDER

Your family may wish to sign Konstanze Allsopp's petition (see *Vision 2007-1* for further information and comment):

<http://petitions.pm.gov.uk/ME-is-real/>

We the undersigned petition the Prime Minister to get the Health Service and medical profession to accept the WHO classification of ME/CFS as an organic neurological disorder and not as a psychosocial syndrome.

Deadline: 22nd January 2008

Signatures to date: 6,735

Remember The Children



The ME Awareness Day concert in Brentwood Cathedral, organised on behalf of the Trust by the Rev Philip Joy and colleagues, lifted the spirits of us all. Philip suffers with ME and his own work was performed as part of the concert.

Soprano Jackie Pittman gave us *Climb Every Mountain* and *Russalka's Song to the Moon* by Dvorak. Her glorious voice filled the Cathedral.

St Bonaventure's Boys' Choir, who recently performed in the Royal Albert Hall, set the Cathedral alight with their gospel music: *Lord have mercy - lamb of God* and *The Blood Song: Doesn't matter what colour you are, so long as your blood was red*.

Ella Joy, who posed for the cover of *Young Hearts* in 2004, played us *Salut d'Amour* by Elgar. Poetry from *Young Hearts* was read by Jane Colby, quoting from Terry Waite's preface to the book: 'Something creative can come from the deepest grief'. She said she believed that the role of the Trust was to help raise the spirits of children and young people with ME as well as giving practical help.

As a Partner Group of the Young ME Sufferers Trust, Solihull & South Birmingham ME Support Group would like to send you our very warmest wishes for your 'Remember the Children' event on Saturday May 12th.

We congratulate the Young ME Sufferers Trust for doing all that they can to raise awareness of just how

serious and life changing the illness of ME can be, especially for young people.

Our hearts go out to all the children who suffer from ME, their families and their carers. You will be in our thoughts tomorrow and always.

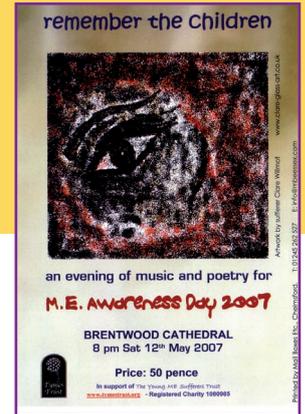
The Trust has many Partner Groups around the UK. We help them with their work and

they have permission to reprint articles from Vision. If your local group would like to become a Partner Group to The Young ME Sufferers Trust, send us their contact details and we'll do the rest.

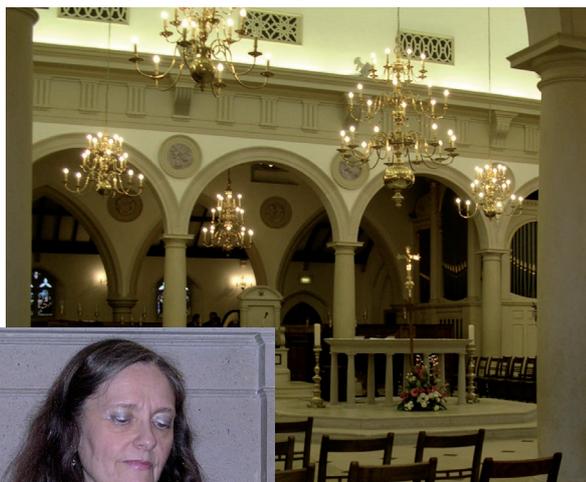


Eye motif by severe sufferer Clare Willmott

The dynamic Turner Ensemble relaxing after performing the premiere of Harp Trio by Philip Joy; led by award-winning harpist Eleanor Turner (www.eleanorturner.com) with cellist Rowena Calvert (www.rowenacalvert.com) and violinist Rhys Watkins.

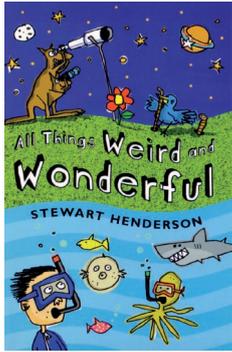
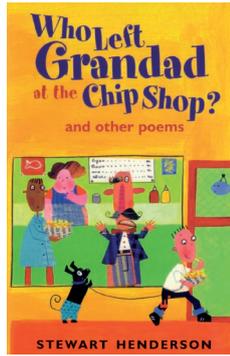


Fifteen-year-old Elliot Bryant gave an inspirational performance of Spring by Vivaldi



Meet The Team

Stewart Henderson, poet, songwriter and broadcaster, has presented *Questions Questions* on BBC Radio 4 for four years. He entertained everyone with poetry readings from his books, and a moving poem about ME written especially for this occasion.



Dear Philip

Saturday was a very special evening. Do keep me posted on developments. You and your colleagues are doing a remarkable thing.

*Best wishes
Stewart*



Imagine Me

Imagine your heart in cling film,
your lungs in solitary confinement,
your blood shivering,
your breath held down,
your energy behind bars,
your mind in a cul-de-sac.

Imagine a butterfly overwhelmed
by the thought of a meadow,
or a wizard too exhausted to hypnotise his cat
into believing mice are not the enemy,
imagine a castle made of tissue paper,
and hence, defenceless against hostile giants.

Imagine long days of gauze and guilt
where the cold streets are a contradiction
and people appear as far off,
in a heat haze,
nothing defined.

Imagine interrogating yourself
with you playing both Good Cop and Bad Cop
shouting and demanding to know
what you did with your spirit
then offering yourself a consoling biscuit,
none of this is your fault.

[read the rest of the poem at www.tymestrust.org]

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Thanks Again...

On June 14th, for the second year running, Sir John and Lady Carter held an open air Shakespeare production in aid of The Young ME Sufferers Trust in the grounds of their beautiful home. The Southend Shakespeare Company presented a sparkling performance of *The Taming of the Shrew* that had the packed audience shaking with laughter. Our thanks to everyone who attended and contributed. Keith Harley and Jane Colby represented the Trust and were invited guests at our hosts' delightful champagne picnic. £750 was raised for the Trust's work. This included a generous personal donation from Sir John.

Join the Team

Would you like to be a friendly voice on the phone? Do you have press experience? Do you like raising funds? Call to discuss how you could help our work, all from your own home. Thank you!

MEA Statement

The ME Association is cementing its growing relationship with The Young ME Sufferers Trust by publishing a major article by their executive director Jane Colby. In *Schools swept by ME plague* Jane reflects on a major headline 10 years ago which changed the way people thought about ME in children and young people.

Jane has also written a leaflet *ME, Children and Young People*; order form at www.meassociation.org.uk.

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.



U 2 Do

Susie Jayasinghe draws you another fabulous scene to colour...

Things 4



Tell us the story ... who are they? Where are they, and when? What's in the bowl? What happens next? First Prize is £10 worth of books from CGP. Runner up prizes too.

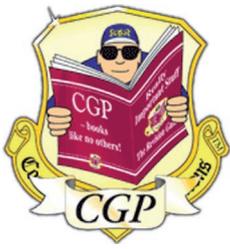
Bring the picture to life with pens or pencils. We'll print as many as we can, and send you our special new art prizes!

Colour a photocopy if you don't like cutting up Vision. We'll return it if you send an A4 envelope with a Large Letter stamp. We can't wait to see yours!

Name
Age
Address
Postcode



THE MEETING



WIN £10 OF BOOKS

We recently received a lovely letter from a young lady called Shannen Dabson who has received support from The Young ME Sufferers Trust. Shannen has used a lot of our books whilst she has

been studying at home - she even sent us a picture of her with some of our books!

At Shannen's request, we are pleased to enclose a £10 Gift Voucher to be used as a prize. [See page 12]

Wishing the Trust every success in the future

Katie at CGP

Shannen is the Trust's Young Advocate. Thank you Shannen and CGP.



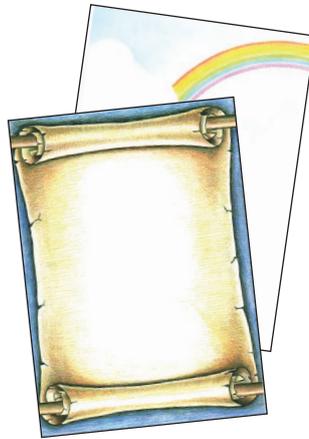
SPIDOKU

Lisa Dabson has sent us a special Seb Sudoku! To solve it, fill in the blanks so that each row, each column and each box contains all the letters in SPIDER.

		I	E		
D	E	R		P	S
P		D		E	I
I		E		S	
R	D	S	P		
	I			R	

We liked the idea so much we decided to give you a really hard one too! This is a Sudoku-X: each column, each row, each box and each diagonal must use all the letters in SPIDER.

	I				
	P	E			
				P	
E			P	R	
				S	



PAPERCHASE

We have packs of decorated papers, suitable for your printer (great for a poem or letter) or to write on by hand. Price £1.50 for 10 assorted sheets. If you'd rather send for 10 the same, choose a design from: sunflowers, fireworks, rainbow, scroll, moonlit lake, trees in mist.

(We have Christmas papers too! If you'd rather a pack of those, let us know.)



My Room

My room is often quite a -----

*Stuff I've hoarded, bears to cuddle,
Stickers on my window pane*

To brighten days of cloud and -----

Leaning back upon my -----

I see my neighbour's weeping willow

Swaying gently to and ---

As Autumn evenings come and go.

My room is shady, fresh and ----

Sometimes I use it as my school!

My shelves hold books and DVDs

A tissue box for when I -----

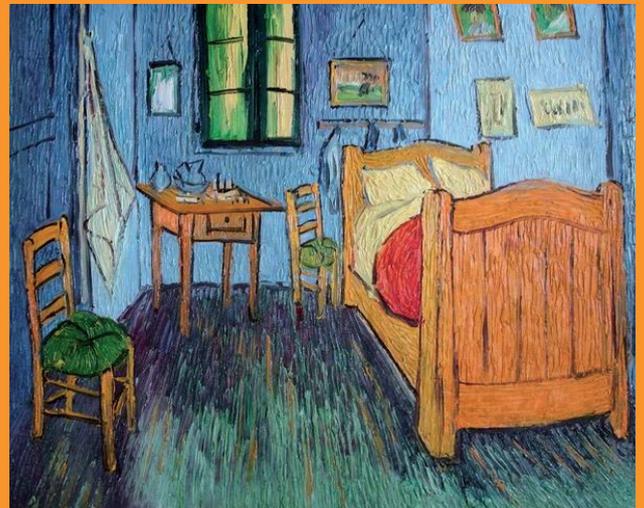
My calendar - that's on 'September'...

There's something else I can't -----.

What's missing from my list? Not Ted...

Oh I forgot! My comfy ---!

Find the missing rhymes. If you get them right, we'll send you a prize! Remember to count the dashes - one for each missing letter.



Vincent Van Gogh didn't have any DVDs...

PHOTO GALLERY

We're collecting photos of our members. Send us a good one of you and tell us if you'd like to be in Vision!

Chloe and Amber with Seb





Yvette Cooper MP is now Minister of State for Housing with the right to attend cabinet meetings. When she was Minister for Public Health, Yvette was interviewed by Jane Colby about her own experience of 'ME'.

J Yvette, thanks for joining me.

Y Hallo!

J Hallo! When did you first realise there was something seriously wrong?

Y Well, I caught 'flu' one winter, just the same as everybody did, had a temperature, that kind of thing, but the 'flu' just never went away, and it just didn't lift and you kept thinking 'Well, tomorrow, surely, I must feel better,' and it just didn't. The temperature went away but I just had terrible flu symptoms that just stayed and stayed and stayed.

J Was there much pain with this?

Y Not really, it was just a feeling of being ill, just feeling tired and achey but not really pain, just this sort of strange flu-like fatigue.

J I'm interested that you use the word 'ill'. A lot of people say they feel ill rather than just tired. Would you distinguish between those two feelings?

Y Yes, definitely. It's like the difference between - I don't know - feeling sick and having some deep stomach pain, you know - there are different feelings that you have. I felt ill, I didn't just feel tired, I felt ill. And I think you know the difference. You know the difference - when you feel tired after you've done a three mile run, you feel tired. When you feel ill with ME you feel very different.

J Yes. And how bad did it actually get in your case?

Y Well, I remember spending weeks at a time just watching Richard and Judy and watching day-time television and not being able to get very far from the sofa - I could manage it across the road, I could get a newspaper, I could bring

it back, and then I'd have to have a rest for half-an-hour before I tried to read it. And yes, it was pretty grim, but in retrospect what I remember is all those day-time soap operas that I watched at the time!

J That tends to be a bit of a pattern in ME, doesn't it? When you do something and then you have to recover from it, and then you do something else.

Y Yes, I think everybody has to find their own pace. But I certainly found I could work it out - it was as if I had a certain amount of fuel in me for the day and I had to choose how to use it. And I could use it going to the shops to get a newspaper, or I could use it speaking to a friend who might come round to visit, but maybe I couldn't do both. And it was just working out every day, you've got - almost like a particular allowance of energy that you can use, and how are you going to pace it and how are you going to rest in between in order to get through it?

J Are you sure you haven't read my book? It sounds as if you're talking my book back to me! [Joint laughter]. So how did it really affect your lifestyle? It sounds as if it had to change completely.

Y Well I was ill for a total of three years altogether and the first year I couldn't work, I had to give up my job, and I was at home for the whole time. I could do bits of things occasionally, but really had to be careful. I couldn't go back to work.

I then had a year after that of working part-time, and then the third year of having to take it just a bit careful - you know, not pushing it too much, working full-time again but taking it careful. And now I'm exactly the way I was before I ever got ill. It took three years to get it out of my system completely I think.

J And it's interesting what you say, because what you were doing is what's technically been called 'pacing' your activity, by the sound of it, whereby you don't do anything too fast and you don't do too much. Is that a good description - pacing - of what you did?

Y Yes, I think so. It was just - you know - try a little bit more, and if it doesn't work out, OK,

well, just leave it a bit, until you do feel up to doing it, and not rushing too fast. I kept thinking, 'Oh, by Easter I'll be back working full-time,' or, 'by the Summer I'll be back working full-time,' and you just have to actually not set yourself too many targets and just think well, you might get there by Easter, on the other hand you might not. So just see how it goes and stick with the part-time if that works better.

J So you had to develop patience, really, didn't you?

Y Yes. Terrible! [More joint laughter]

J I know. Who actually diagnosed you? Was it a GP or a consultant?

Y My GP said very early on, he suspected it was post-viral fatigue and referred me quite early on to a specialist - it was actually a virologist I think - at the Royal Free Hospital, who tried all kinds of other tests and he didn't actually use the word 'ME', I don't think. I think he talked about Chronic Fatigue Syndrome. Whichever it's called, you know how you feel.

J Well, I absolutely agree with you. So three years is a long time to be getting through an illness when you're really used to, perhaps, a flu that's only a few weeks at most, isn't it? Did you find the support of people round you was very important through this?

Y Yes, I did. I had a lot of people who supported me, and I used to not rely on any one person too much - because you do feel the need for support and the need for a lot of people to help you. I was sharing a flat with three other people at the time, but rather than burden them all the time with the way I was feeling, I used to talk to other people and I had a lot of close friends who were extremely supportive and helpful throughout.

But, yes, it is strange, nobody can understand it, you know? Most people are used to being impatient if they've only been ill for two days. You think, 'I must be getting better by now.' And when it's months later and you're still looking exactly the same, it is hard for people to understand. But I found people were very supportive so long as you didn't demand too much of them all the time.

J Presumably you needed a certain amount of practical support too, as well as just friendship.

Y Oh yes, we had a lot of arguments about me not

doing enough cleaning up in the house! And not doing enough washing up as well, because I said I was too tired to stand up long enough to wash up. So we did have a few disputes about that along the way.

J Were you ever asked by the specialist you saw to see a psychiatrist? A lot of people are asked to see a psychiatrist.

Y No, I was asked by my GP, who referred me to a counsellor - or maybe it was a psychiatrist - who I had one session with, who agreed that yes, I was having a bad time because I was ill, but there was absolutely no psychiatric cause at all. And that was never pushed on me at all. I figured, actually, that if I went and talked to them, it would make quite clear to them that this was not a psychiatric cause or illness, I had no problems in my life before I got ill, I just got 'flu'.

... you're saying your body just got on with it and healed you if you gave it time ...

Certainly, after I got ill, after I'd been ill for two or three months, then it did become a bit grim and you do start to feel quite depressed having been ill for so long, but the causal link went

from being ill, to getting depressed and having a hard time about it, and certainly not the other way round at all.

J Were you given any medication at all, at any time?

Y No, after I'd been ill for about four or five months, and it was just grim coping with it, I tried Prozac for a while, which cheered me up but it didn't cure me physically at all, so it didn't make me feel physically any better, or any better able to do things.

J Basically, what you're saying is that your body just got on with it and healed you, if you gave it time.

Y Yes, I think so. Who knows how and why I got better, or when? Who knows whether it was time, or what it was? I started swimming after I'd been ill for about a year and that helped for me, but everybody's different. When I tried walking, if I walked any distance it was still really hard.

J Well, you're obviously feeling fine now. I will just ask, how did you keep yourself going through the most difficult times? Because this is what people say is the hardest thing, just keeping going.

Y I used to have routines. Quite clear routines. Not routines that challenged me, but routines of things I did: what time I got up, which was always late - the

first thing I did was have a bath, just a nice, long relaxing bath; then I'd switch the television on and watch Richard and Judy for a few hours; and then I might have lunch after that.

And I had quite clear routines to get me through the day, of things that I was going to do, so that at no point in the day did I ever have a point where I just lay there and thought, 'I don't know what to do with myself now because I can't do anything, and all I'm doing is thinking about being ill.' And so, maybe it would be a friend ringing me up at a particular time, or something I had to do at a particular time, just give myself things to not allow myself to just wallow in being ill, to not allow myself to think about being ill too much because you just turn yourself bonkers if you do that.

J Absolutely. That's exactly what I always say to people - put something into every day that you can enjoy. Well - thank you very much, I've really enjoyed talking to you.

Y Thank you.

*Interview recorded at Sky News, Westminster
Copyright © Jane Colby*

Yvette's continuing success story is an encouragement to all, whether they've been diagnosed with 'ME', 'CFS' or 'Post Viral Fatigue Syndrome'. We advise that you listen to your own body as Yvette did, and get support to help you get stronger in your own time.

Link between ME and enteroviruses confirmed

The enteroviral cause for ME was the subject of Jane Colby's book *ME - The New Plague* published in 1996, which she is currently rewriting. In it she explored the link with poliomyelitis.

The hypothesis of the book has just been validated in a new study by California infectious disease specialist John Chia MD, whose son had CFS/ME. Four out of five patients showed chronic enterovirus infection in stomach tissue biopsies. Mimicking colds, glandular fever and flu, enteroviruses target the brain, muscles and heart.

Dr Chia says endoscopy could be a relatively simple test to confirm persistence of enterovirus infection and study responses to antiviral treatments. Writing to Jane (who had proof her own case of ME was enteroviral) he said: 'Many of us were totally fooled by these enteroviruses. I am glad you believe it and had evidence to show it.'

Hi. I have received your Welcome Pack with much appreciation. My query is: 'Is ME now classified as Chronic Fatigue Syndrome?' My GP said it was. I am sure if I read through all your excellent documentation I will find the answer but I have read so much about it at the moment, my mind boggles. We are waiting for an appointment with a Consultant Paediatrician and I do not want to appear uninformed.

Many thanks, Elaine Charles

Elaine,

Your GP is not correct. On the back of each *Vision* we print the World Health Organisation's classification reference number for Myalgic Encephalomyelitis (ME) as a neurological disease. It is not called Chronic Fatigue Syndrome (CFS). The British Government recognises World Health Organisation classifications.

Although the Royal Colleges Report of 1996 (mainly produced by psychiatrists) recommended the use of the term CFS, most patients and a number of doctors maintain that this was an unscientific term. You can find an article about this on pages 14-15 in *Vision 2007-1*, called *Why CFS is not ME*. It is an excerpt from our submission to the National Institute for Clinical Excellence (NICE) and covers how the term 'CFS' was born. CFS consists of a wide group of symptoms originally listed by researchers who chose their own symptom profile to research. To confuse matters further, different symptom profiles have been compiled by other researchers and also called CFS. In the Trust's opinion, this term should never have come into clinical use as it never described a discrete illness.

The Dept of Health has adopted the combined term CFS/ME. You will see this on Dept of Health documents.

It is true that the 'medical establishment' generally uses the term Chronic Fatigue Syndrome. But many use an even looser term - 'chronic fatigue'(CF). Many doctors don't know of the difference. 'Chronic fatigue' is not CFS, it is just one single symptom, which may be physical or psychological in origin. Medical

is ME now classified as Chronic Fatigue Syndrome?

professionals often muddle CFS and CF, which is not surprising given the confusing terminology.

Despite all these problems, the disease of ME, even if not always referred to as such, remains a potentially severe neurological illness. It is often trapped under the heading of CFS rather than being considered in its own right. Research shows that a significant proportion of people with so-called CFS have a symptom profile and reaction to treatment just like 'ME' as it was defined in the 1950s. It is a polio-like illness following infection. Until significant recovery has taken place, people with ME do not react well to effort, either physical or mental. Effort can cause severe relapse if it is too much for their bodies.

School attendance is a significant cause of relapse in children and young people as it is so physically and mentally demanding. Other means of education are being used to great effect to help the body to heal and also to help the child achieve, thus satisfying their legal right to a 'suitable education' for their individual needs. The Trust advises families to seek such modifications to their child's education until they are satisfied that all that could be done is being done.

Jane

Statement by the Department of Health

As you may be aware, the World Health Organisation (WHO) classifies CFS/ME as a neurological disease, and in the International Classification of Diseases it is coded G93.3. The Government has long recognised the WHO classification of this debilitating and distressing condition. CFS/ME is a chronic illness and health and social care professionals should manage it as such.

David Winks
Department of Health

Dr Charles Shepherd

In his book *Living with ME*, Dr Charles Shepherd of the ME Association says: 'I still believe that Dr Melvin Ramsay's original definition is the best clinical description of the lot!' Dr Shepherd also comments on the following features of ME in Melvin Ramsay's work:

- *Circulatory impairment* involving cold extremities (hands and feet), increased sensitivity to climate change, and episodes of sweating

- *Cerebral dysfunction* involving impairment of memory and powers of concentration. Other typical symptoms include difficulties in completing a line of thought, mixing up words, sleep disturbance and emotional lability.

Ramsay Definition of ME

Dr Melvin Ramsay was born in Lancashire in 1901. From 1926 to 1935 he was a GP in South Africa, then returned to the UK where he practised at Fulham Hospital and then at the North Western Fevers Hospital, becoming Deputy Medical Superintendent. He instructed nurses and medical students in the management of infectious diseases and when the Fever Hospital was taken over by the Royal Free Hospital, he was consultant physician to the Infectious Diseases Department. He was also consultant in smallpox to the Ministry of Health and lecturer and examiner in infectious diseases for postgraduates training for the Diploma of Public Health [...]

The clinical identity of the myalgic encephalomyelitis syndrome rests on three distinct features, namely:

- A unique form of muscle fatiguability whereby, even after a minor degree of physical effort, three, four or five days, or longer, elapse before full muscle power is restored;
- Variability and fluctuation of both symptoms and physical findings in the course of a day; and
- An alarming tendency to become chronic

If we take the well known condition of post influenza debility as an example of a postviral fatigue state, we see that in all these three particulars it constitutes a complete contrast.

From *Myalgic Encephalomyelitis and Postviral Fatigue States: The Saga of Royal Free Disease (Second Edition)* by A. Melvin Ramsay MA MD (published by the ME Association).

Byron Hyde MD

The Trust has published the new *Nightingale Definition of ME* by Byron Hyde MD at www.tymestrust.org/tymespublications.htm which focuses on newly available physical evidence for the brain dysfunction referred to by Melvin Ramsay and other notable ME experts. See also *Vision 2007-1* for an interview with Dr Hyde and a summary of the key features. At www.tymestrust.org/tymesmagazine.htm or printed copies available for £2.95.

On 22nd August 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*

The NICE remit was to prepare guidance for the NHS in England and Wales on ‘the assessment, diagnosis, management of adjustment and coping, symptom management, and the use of rehabilitation strategies geared towards optimising functioning and achieving greater independence for adults and children of CFS/ME’.

The *Guideline*, *Quick Reference*, patient / carer booklet and related documents can be downloaded from www.nice.org.uk/CG53.

Some doctors may only read the *Quick Reference* which does not include this (from the Introduction):

The World Health Organisation (WHO) classifies CFS/ME as a neurological illness (G93.3), and some members of the Guideline Development Group (GDG) felt that, until research further identifies its aetiology and pathogenesis, the guideline should recognise this classification. [the Trust concurs with this view] Others felt that to do so did not reflect the nature of the illness,

and risked restricting research into the causes, mechanisms and future treatments for CFS/ME.

This disagreement within NICE indicates that even the WHO’s expertise is unlikely to be heeded by some medical professionals until classic ‘ME’ (the neurological illness) is unscrambled from ‘CFS’ (a collection of symptoms too imprecise for a unique diagnosis).

We believe this makes our stand in advocating the separation of ME and CFS even more important; we will continue to highlight this issue.

Press Release Excerpts

On diagnosis:

If a child or young person under 18 years old has symptoms of possible CFS/ME they should be referred to a paediatrician within 6 weeks of first seeing their doctor about the symptoms.

After other possible causes have been excluded, a CFS/ME

diagnosis should be made after symptoms have persisted for 4 months in adults, and after 3 months in a child or young person (in consultation with a paediatrician).

On management:

An individualised management plan should be developed with the person with CFS/ME and they are in charge of the aims and

goals of the overall management plan.

On Education:

Follow guidance from the Department for Children, Schools and Families (see www.dcsf.gov.uk) on education for children and young people with medical needs, or equivalent statutory guidance.

The Good

NICE has acted on a number of the Trust’s recommendations and those of other ME organisations (our recommendations are in *Vision 2002-1* p14-15 at www.tymestrust.org/tymesmagazine.htm; printed copies available).

NICE emphasises prompt diagnosis and doctors are urged to ‘acknowledge the reality and impact of the condition and symptoms’.

NICE prescribes ‘shared decision-making’ between health professionals and patients and emphasises the individual’s ‘right to refuse or withdraw from any part

of their treatment plan without it affecting future care.’

Quote this if you feel coerced into management plans that are unsuitable for you. NICE advises that the doctor is not ‘in charge’ - you are. Use your own judgement; this is a difficult illness for someone to appreciate from outside.

NICE recommends a flexible approach to education, with home tuition and equipment that ‘allows a gradual reintegration into education’. This does not say ‘reintegration to school’, reflecting our recommendation that education should not necessarily mean school

attendance. There are other means of learning which may be more suitable, such as the interactive online schemes for which the Trust is in partnership with Nisai Virtual Academy.

NICE advises doctors: ‘do not use time in education as a sole marker of progress of CFS/ME [this was a strong recommendation by the Trust], and ensure a balance between education and home and social activities.’ We know that school attendance has unfortunately been used as a marker of recovery without reference to whether symptoms are provoked, or whether attendance is hindering academic progress.

NICE - the CFS/ME Guideline

the Good, the Bad, and the Ugly

The Bad

NICE discourages daytime naps in the name of ‘sleep hygiene’ a dreadful term (who invented that?) with overtones that someone who cannot sleep in the prescribed way is dirty. It flies in the face of evidence from ME experts that daytime napping promotes health and ignores the Mediterranean siesta tradition as if that were abnormal.

NICE advocates management plans based on the outdated concept that the muscles are merely ‘deconditioned’ from lack of use. We disagree: physical disability and illness require time for healing before demands are made on the muscles. Inappropriate exercise is a recipe for relapse. Patients made worse by such treatment may take legal action or report the therapist in order to help protect other patients.

NICE advocates that Cognitive Behavioural Therapy (CBT) and/or Graded Exercise Therapy (GET) should be offered to people with

mild or moderate CFS/ME and provided for those who choose it, saying that there is the clearest evidence of benefit for these approaches, and that ‘sleep hygiene’ should also draw on the principles of CBT and GET. The Trust’s information is that only those who do not have classic ME are helped by graded exercise, unless the body has healed sufficiently to withstand progressive increases in effort.

NICE states that the Graded Exercise Therapist should discuss ultimate goals that are important to the person eg a ‘twice daily short walk to the shop, a return to cycling or gardening or, for people with severe CFS/ME, sitting up in bed to eat a meal’. Increases of up to 20% in effort are recommended with advice to the therapist to ‘explain symptoms and the benefits of exercise’. We would like to hear any such explanations you are given.

NICE recommends that the intensity of Graded Exercise should be

increased in stages, leading to aerobic exercise. This puts up the heart rate. It contravenes advice from experts such as Professor Paul Cheney: ‘The most important thing about exercise is not to have them do aerobic exercise. I believe that even progressive aerobic exercise [...] is counter-productive. If you have a defect in the mitochondrial function and you push the mitochondria by exercise, you “kill” the DNA’ (1999, International Congress of Bioenergetic Medicine, Florida).

NICE advises: ‘Offer people with severe CFS/ME an individually tailored activity management programme as the core therapeutic strategy,’ based on the same principles as Graded Exercise (above). Yet the Trust has formerly severely ill members who have greatly improved over time with no treatment at all, and others whose health has declined after accepting this treatment. We caution care.

The Ugly

NICE published comments received on its 2006 Draft guideline (*we thank Tom Kindlon, Vice Chair, Irish ME Support Group, Partner Group to The Young ME Sufferers Trust, for researching the NICE website*). Many have caused concern. The following were submitted by St Bartholomew’s Hospital (Barts):

We emphasise that CBT and GET can also help those small number of patients who do not wish to return to normal health.

Equipment and aids may hinder recovery as much as help it.

In response to the NICE Draft text For adults and children with moderate or severe symptoms,

provision of equipment and adaptations (for example, a wheelchair, blue badge or stairlift) to allow individuals to improve their independence and quality of life should be considered, if appropriate and as part of an overall management plan, Barts said: We disagree with this recommendation. Why should someone who is only moderately disabled require any such equipment?

There seems little recognition by Barts that people can be made more ill if such practical help is denied. We feel that their comment shows a serious misunderstanding of the illness as being perpetuated by psychological factors rather than

physical limitations. We are not aware that children wish to depend on a wheelchair, a stair-lift or hoist for longer than necessary. Barts also states that CBT / GET can help the severely affected - discussed above.

We do not agree that drug treatment should be initiated at lower dose than in usual clinical practice.

This contradicts evidence on drug reaction given to NICE.

Weight loss is not part of CFS/ME at any age.

The NICE Guideline Development Group itself disagreed: ‘The view of the GDG is that some children may lose weight and require nutritional support.’

SEB'S MANOR



Name the Sympathy Teddy

Helen Brierley wrote:
 'I think the Sympathy Teddy should be called Barney as it's a brilliant name! Also I



don't think he should be all bandaged up, but should be sat in a wheelchair with some groovy sunglasses on to avoid that sun!! I could relate to that, when my ME was worse!' Stewart was another good suggestion, and Indra Wignall said: 'I think he should be Terrence the Tymes Trust Teddy! :D x x x' I like that and so does he. But in the end he chose Doctor Bump (Chloe Halstead) as

it makes him feel important!

All our winners received a Sympathy Teddy fridge magnet of their own.

(If you joined before they were available, you can buy one for £1.50 including post and packing.)

Jodie Halliday

Sebastian Says

All my faithful fans know that I'm in charge of the prizes. Well, you're going to want to enter all the competitions this time BECAUSE I snuck into the House of Lords for tea and they made a huge fuss of me and treated me like an A-list celeb AND they let me buy you lots of House of Lords memorabilia at their special shop. So get busy as soon as you feel able. I'm looking forward to seeing your colourings and artwork and everything else.

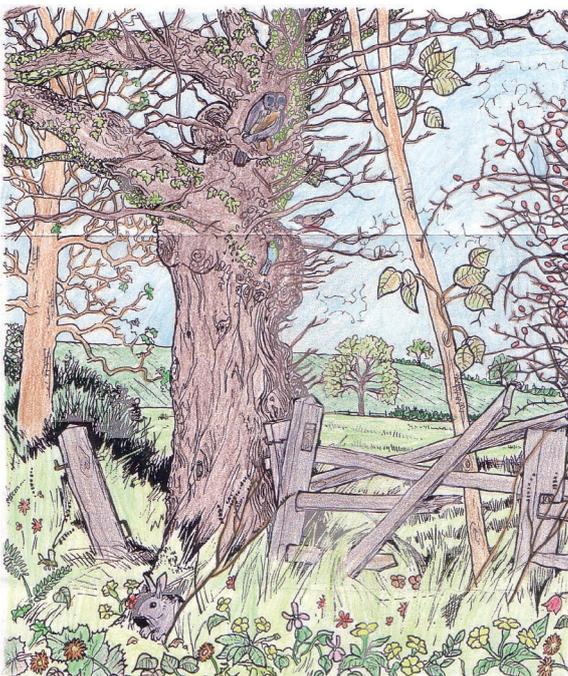
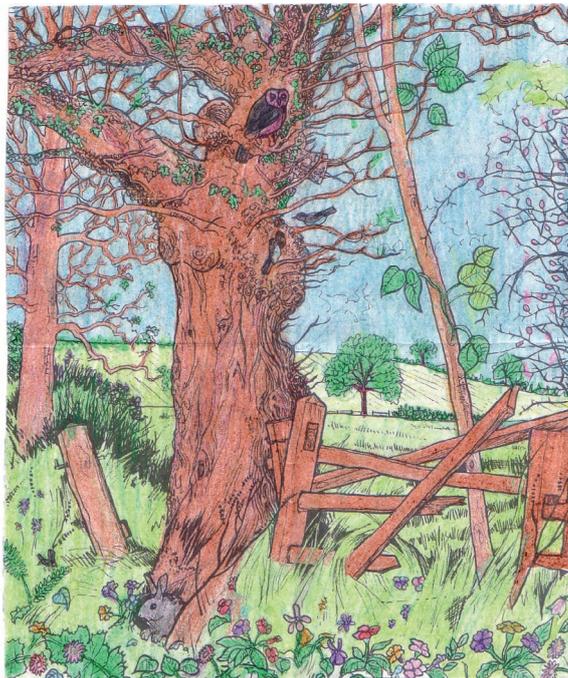
The Terrace where we had tea is very big and I'm only little. Lady Elizabeth was really kind to me - she gave me a ride on her shoulder. So I'm now an Even More Important Spider because I've met the Queen's cousin, who has a great sense of humour! Here is poem I wrote to mark the occasion.

I'm a Very Important Spider
 and my head just grew much wider
 well in fact it grew much bigger
 but that doesn't rhyme - don't snigger
 and don't think I've gone all snooty -
 cos I've brought back all this booty! *

You see, I haven't lost my poetic touch.
 Can you write me a poem?

Seb

*And it's all for YOU! I didn't forget you while I was having such a great time.



I love having all your superb colourings on my page!
 Don't forget to send me yours for next time!

Harriet Hines

BOGTOR BUMP
+



More wonderful sketches from Chloe Halstead. She decorates her envelopes with them too - you should see the postman's face! Well done Chloe. She let me stay with her twice as well, and took great photos for *Vision*. Who is going to let me come and stay with them now, I wonder? Could it be you?!

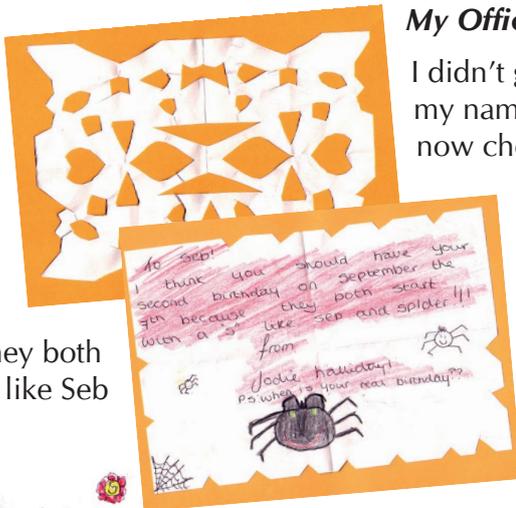


My Official Birthday

I didn't get to choose my name, but I have now chosen my Official Birthday (us important people really need two, you know?)

To Seb

I think you should have your second birthday on September 7th because they both start with an S like Seb and Spider.



You sent me suggestions and I chose

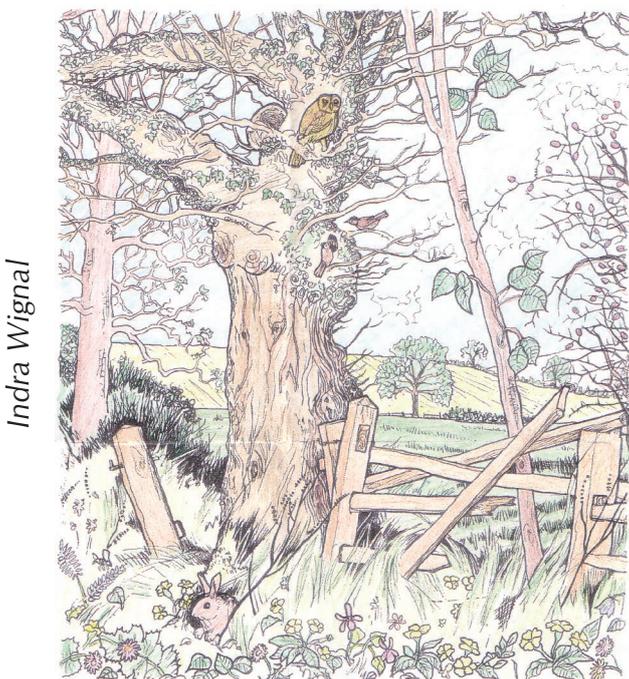
June 15th. Put it in your diary for next year - let's see who remembers!

June's important to me because the Trust's anniversary's in June. And (secret) Jane's mum's birthday was June 15th! I sent prizes to everyone who made suggestions. I'm a Very Kind Spider.

Jodie Halliday was very clever - have a look at her letter. What she didn't know was that September the Seventh is my REAL birthday!!! How could she guess that? Spooky!



from Jodie Halliday
PS When is your real birthday?



SEB'S HOLIDAY COMPETITION

I was supposed to go on holiday this week, but with all the important meetings I've been having recently I'm exhausted! So I decided to put all my feet up and think about going on holiday instead. It's turning out rather well - I've been to three countries already, been camping on the moon with Alan the Alien (see *Vision* 2005-3) and some of his relations (we were all going to play golf but we forgot our clubs) and tomorrow I'm having tea with Elvis (actually that bit's real but don't tell anyone). Why not write and tell me all about your virtual holiday? Where are you going, and who with?



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



A letter from ...



Hello, and thank you for such a great service.

I am a new member, and saw in the last issue of *Vision* magazine that members

could apply for free audio books. This would be very helpful to me as I can't read because of poor concentration, yet love books and used to read all the time. Could you please send me a form?

The other thing is please could you send me a Young ME sufferers Trustcard? This would be oh so helpful because I just don't ask for what I need at school as it is too much to go through it all and some teachers aren't understanding. My Mum and I agree that this would be a great help.

Thanks again,
Isabelle Cooper.

Hi! Thank you very much, I received the forms today and will be sending them off soon. It is wonderful what services you offer and I am really looking forward to receiving my audio-books, as I find the loss of reading very upsetting.

The Trustcard will also be a great help as I sometimes become very ill at school because I just can't face going through explaining it all, some teachers don't believe me and others don't understand. This will be a great boost, so I can get extra layers or a snack or sunglasses if I need to, be excused from a lesson or PE if it's needed and many other things. Thank you so much Tymes Trust!!!!

Love Isabelle Cooper xx

This photo is of me a long time before I got ME.

Let us know if you would like free membership of the National Listening Library. Trustcards come with information for your school. Our feedback suggests that most teachers take notice of the card, but if you have problems, let us know.



Many thanks for the free subscription to the listening library as this has been absolutely fantastic for Sarah as she can relax so much easier, now all we need to do is to find a machine that turns off as she falls to sleep so she knows where she is. LOL.

Many thanks,
Jan Coulbert



Sarah says:

This made a big difference to my life, especially when I can't sit up or

take part in more 'active' things. Been able to 'read' books I love again.

Thank you so much for the invitation to attend the Awards at the House of Lords. Though I was very tired afterwards, both Judy and I thoroughly enjoyed our outing - not least the cakes! To go onto the terrace on such a beautiful day was a treat, as was the ride back along the Chelsea Embankment in our taxi with the wonderful bluey, pink opalescent sky. Though I live in London, I very rarely travel into the centre now, and I really appreciated the beauty of the city that afternoon.

I think the event was very worthwhile, both to recognise the youngsters' achievements (so many young people struggle with

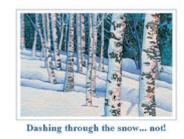
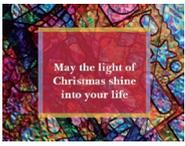
feelings of worthlessness because they are ill) and to get declarations of support from prominent people. I notice the latest issue of *Vision* has statements from the Prime Minister and the Leader of the Opposition. I think such support is very valuable when we have such an uphill struggle against some vested interests.

I was very impressed with the *Guardian* front page you displayed, which I had never seen before, though of course I know your and Dr Dowsett's study. Such an excellent piece of work, clearly showing the epidemiology of the illness is consistent with an infectious cause - so frustrating

that its findings, like those of other studies, are ignored by those who don't like them, however valid they may be.

I do very much appreciate the work you do personally for people with ME, which I know has come at a price because of your own illness. There must be many families in very hard places who had no-one to turn to and were able to turn to The Young ME Sufferers Trust. You do make such a difference to all of us with ME.

With thanks and best wishes,
Catriona Courtier
(Friend of the Trust)



Save the planet - and my energy!

Once upon a time, before we all went metric, there used to be a thing called 'a dozen'. Some of us have fond memories of dozens, so our special 'Save the Planet - and My Energy' Christmas postcards come in dozens. If you all buy a pack of 12, think how much energy we'll save! All cards have catchy ME friendly messages, so you don't have to write one. And of course, no envelopes to lick. Shirley Conran uses postcards all the time - much easier.

Price just £2.80 for 12 including P&P.

PS And the proceeds will help fund our services to families.

See them in the colour version of the magazine at www.tymestrust.org.



Two of Mr Harley's Le Blanc bears from Chamonix have found homes in the same house! That has to be a first.

Thank you for the lovely sweet cuddly bear. He is called Wafers. My Roby doll loves cuddling him and I do too. I have loads of cuddly toys so he won't have trouble finding a friend! At the moment his friends are Fudge (my tiger), Ruffles (my leopard), and Snowy (Chloe's white bear). And ME!! I cuddle him at night and love him very much. Thanks again.

Love
Amber Halstead

Comm-u-ni-cate!!

Our newest 11-year old member is 'mad about Dr Who' and collects Dr Who stuff. He'd love to hear from other Dr Who enthusiasts (among whom you can include Mark and Jane!) so send in your postcards or messages for him. We'll take it from there. (We haven't printed his name as we're doing this as a surprise!)

Thank you very much for my birthday card it was lovely to read it on my birthday. It was a fantastic surprise to see Seb, in the latest magazine from when he came to stay. I shrieked out loud with excitement when I saw him, I hope I didn't frighten him. Thank you for everything you do to try and make



the M.E. World a better place to be. Love Cheryll Neyt
Seb says he has supersonic hearing (naturally) and so he did hear you, but recognised you as an old friend, so that was all right!

Love Michelle Cross

Time

Time ticks by
Time ticks on
Time will be
Time has gone
Time moves us onward
And takes us forward
Time is what we look back upon
And look toward
Time is constant
Time is ahead
Time is where we have,
And will, tread
Time is there in our joy
And in our strife
Time is our course
Our rhythm in life
Time is there
Around every bend
When will Time's journey
Come to an end?
Time will never leave us
Yet never comes back again
We will live
And we will die
With Time, so then,
When Time ticks by
And Time ticks on
Know that Time will be
And Time has gone.
Cerith Messenger





Open Champion Wishes You the Luck of the Irish!

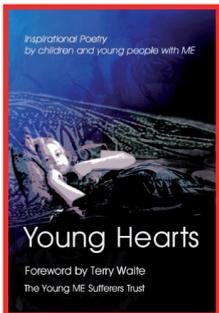
Padraig Harrington won the Open play-off at Carnoustie not just through skill and hard work, but also something we all need: the self-belief to just hang on in there. Jane (who's half-Irish) first met Padraig when her improving health led her to try golf. His advice? 'Keep on with the lessons [hits spectacular shot with a lob wedge] and when you can do that, you've cracked it!'



Hi Jane,

It is nice to hear from you and get positive feedback to encourage me to do what I am doing. I hope that this note does likewise and similarly encourages you to continue your great work in supporting and encouraging the children - I wish them the best of luck.

Padraig Harrington



Young Hearts Sky Dive

PLEASE SPONSOR JADE'S COURAGEOUS FRIEND AMI!

Ami Lindsay says: 'I am doing a sponsored Sky dive for my 18th birthday in November. I have chosen this charity as I was good friends with Jade Scarrott, and throughout years of growing up together we had always planned to do something for a joint 18th.'

Please help Ami in her bid to support the Trust's work. You can download a sponsor form for you and your family at www.tymestrust.org/donations.htm (there's a secure payments button there too).

Taken from her family and us in a tragic road accident, Jade was the 14-year-old with ME who inspired Young Hearts with her poetry. This beautiful illustrated book was published in Jade's memory and launched in Warwick Castle by the Archbishop of Canterbury's former Special Envoy, Terry Waite CBE. Wonderful poetry from youngsters with ME to melt the hardest of hearts - a perfect gift for just £7.95. See a TV interview at www.tymestrust.org. Young Hearts Day is Thursday 29 November - our special day to remember all young people with ME.



What Makes You Happy?

Have you read the winners in the Shirley Conran writing competition? Good news - we're running another! Same challenge - tell us what makes you happy. Write on a postcard (cut off the front of a used greetings card if you can't get out to buy one).

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