

*The Young ME Sufferers Trust*

*2005-3*

*£2.95*



# **VISION**

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COUSIN HOSTS  
FRIENDS  
RECEPTION**

Lady Elizabeth Anson

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## THE YOUNG ME SUFFERERS TRUST

*Registered Charity Number 1080985*

Founder Patron	Lord Clement-Jones CBE
Patrons	Earl Howe    Barbara Windsor Shirley Conran Terry Waite The Countess of Mar
Friends Patron	Lady Elizabeth Anson
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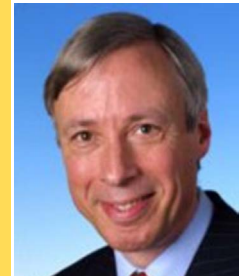
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*Cover : Moley and Bandit review an early copy of Vision*

# Our Patrons



Lord Clement-Jones CBE



Earl Howe



Shirley Conran OBE



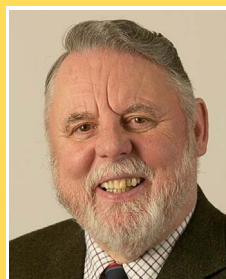
Lady Elizabeth Anson



The Countess of Mar



Barbara Windsor MBE



Terry Waite CBE



# Vision - The Project

As we enter upon 2006, I am happy to report many extremely encouraging developments.

**welcome**trust

Our website [www.tymestrust.org](http://www.tymestrust.org) has been chosen by the Wellcome Trust for inclusion in the UK Web Archive pilot project.

This is a great honour and indicates the value that has been placed on the website as a national resource. The archive will take copies of the site at regular intervals to hold in perpetuity.

All our existing publications are now on our website. We will continue to produce new publications to add to this bank of knowledge.

Our Executive Director, Jane Colby, has given evidence to the parliamentary Select Committee on Special Educational Needs, indicating the urgency of training teachers in the needs of pupils with ME/CFS. This evidence may be read at [www.tymestrust.org](http://www.tymestrust.org) on the publications page (see The Tymes Trust View).

Jane and I were granted a personal meeting with Education Minister Lord Adonis and Lord Clement-Jones CBE, at which we discussed other serious problems in Local Education Authorities. We shall report further on this at a future date.

The Trust was also invited to the Department of Work and Pensions to advise on modifications to the proposed new ME/CFS guidelines for Disability Allowance. We emphasised that ME/CFS is a neurological illness and that Decision Makers should receive guidance stating that ME/CFS is a physical disease in which people are typically made worse by making physical efforts beyond those that are



*Kerry-Ann Edge*

sustainable. We have been invited to attend a future meeting to discuss the redrafted guidance.

After the last issue of *Vision*, we said goodbye to our designer Kerry-Ann, who, having suffered

severely with ME as a teenager in South Africa, came to the UK and volunteered with the Trust in Essex.

Kerry-Ann has designed for *Tymes Magazine* and *Vision*. As a result of her work with us, she embarked upon and achieved a 2.1 degree in graphic design. She is now emigrating to New Zealand with her husband Michael and takes with us our grateful thanks and good wishes for a bright future.

Mark Colby volunteered to increase his role and now designs *Vision* as well as our website. We are particularly grateful for this, as we know that his professional work in motorsport is so demanding and time-consuming.

A very happy day in Autumn was when the Queen's cousin, Lady Elizabeth Anson, held a champagne reception at her home for sixty Friends and supporters of the Trust. Her personal warmth and openness in sharing her own experiences of ME made this an occasion of enjoyment and encouragement. Children with ME suffer so much and they were of course at the heart of this event.



Our education partners Nisai Education, whose GCSE results have shown a 97% pass rate, kindly supported the occasion. The aims of the day were friendship, increasing the understanding of how ME affects children, and considering ways of raising funds for the Trust's work. I hope that 2006 will see the Friends grow and prosper in these aims and I invite new Friends to join and attend our future events.

You can now see a full colour version of *Vision* at [www.tymestrust.org](http://www.tymestrust.org). Enjoy!

Keith Harley

Chair of Trustees



*Keith Harley*

# Meet Our Patrons



I am delighted to say that, following the House of Lords debate on education for children with special needs, in which I highlighted the needs of children with ME, the Trust's Executive Director Jane Colby, Chair of Trustees Keith

Harley and I met with Schools Minister Lord Adonis to discuss some particularly serious issues.

**Lord Clement-Jones CBE**  
**Founder Patron**

## Lady Elizabeth Anson

The Trust thanks Lady Elizabeth for hosting a Champagne Reception for Friends and supporters of the Trust at her beautiful home. She is delighted that so many people journeyed so far to be with us.



What an enthusiastic party we all made. From the Trust's home village of Stock came Lady Carter and Barbara Grayburn. John Griffin, who three years ago raised £4000 for the Trust on his trek up Mount Kilimanjaro, travelled hundreds of miles yet again, to attend with daughter Lauren; Karen Scarrott, mother of Jade, in whose memory *Young Hearts* was published, also made the trip. Karen, her family and the Warwick Fire Officers raised over £1000 towards the first issue of *Vision*.

Among the many guests was Trevor Wainwright from MERSC; every year, faithful Trevor raises funds towards the Trust's Advice Line. We were delighted that our Royal Mail manager was there with his wife, together with the director of GP Line, members of the Advice Line Team, and Chair of Trustees Keith Harley with Trustee Jennie Whitlock.

We also welcomed Fatima Celestino and Andrea Foster, who run for the Trust, and our wonderful printer Paul Fisher. Author Jill Curtis, who consulted the Trust for her book *Does Your Child Have A Hidden Disability?* and psychologists Lisa Blakemore-Brown and Naomi Burgess were also present.

Dhruv Patel, head of Nisai Education, Preya Dattani and David Teece amazed us with the examination results obtained by our members using the virtual education scheme.

In her 'at home' interview with Jane Colby, Lady Elizabeth recounted memorable moments from her life's struggle with ME while running her business Party Planners.



*Member Daliany Kersh with Lady Elizabeth*

**Jane** I believe you told me that the pain used to get very bad in your feet?

**Lady Elizabeth** The only way I could get the pain out of my hands and feet was to put them in frozen water. Once, when the guests had gone into lunch, I hitched up my frock and put both my legs into the big bin housing the ice for cooling the champagne. At that moment, the bride's father walked in!

*We are grateful to our virtual education partners, Nisai Education, for supporting this Reception.*



*Member Shannen Dabson and her schoolfriend Bethany Dunne with Lady Elizabeth and Jane Colby*

**Lady Elizabeth Anson, Cousin to the Queen, would love to welcome you to the Friends of the Trust. To join, please send your £10 subscription by post or online at [www.tymestrust.org](http://www.tymestrust.org)**



## Shirley Conran OBE

Shirley is delighted with your entries for the Shirley Conran writing competition, 'Answers on a postcard please!'

Her theme was 'What I would like to do this autumn.'

Read the winners on the back.



# In The Spotlight

a new publication from The Young ME Sufferers Trust  
**ME/CFS Guidelines for Educational Psychologists**

### **The Young ME Sufferers Trust finds that unsuitable educational demands are a key cause of relapse from ME.**

The mother of a child whose story features in this guide comments: 'A lot of parents have, and still are, battling with Education Authorities that unfortunately do not have full knowledge of ME. [...] I would urge families to try and explain and to give out information from reputable patient organisations - as recommended by the Department of Health - particularly The Young ME Sufferers Trust, which specialises in the education of children with ME.'

When children with ME are assessed to determine their special educational needs, a key professional in the assessment is the Educational Psychologist.

There has until now been no detailed and appropriate specialist guidance for this task.

Naomi Burgess, an Educational Psychologist with experience of ME, and Jane Colby, former head teacher and severe ME sufferer, have produced the first comprehensive guide for Educational Psychologists to help them plan and carry out these assessments.

**NB** The term ME/CFS has been used throughout the guide because children are increasingly been given the diagnosis of CFS.

The Guidelines are composed of five sections including a Learning Questionnaire for the pupil and parents to complete in order to provide information to help the assessment:

**Assessment of pupils with ME/CFS**

**Disability Discrimination Law**

**One Family's Experience**

**Use of the Questionnaire**

**Learning Questionnaire**

The main section contains a number of short subsections covering key aspects:

*ME/CFS is not a psychological condition*

*Purpose of the assessment*

*Planning the assessment*

*Carrying out the assessment*

*What you need to know about children with ME/CFS*

*The learning context*

*Timescales*

*Content of curriculum*

*Stamina and how it may affect examinations*

*Assessment content*

*Information technology*

*Reminders about sensory difficulties in ME/CFS*

*Flexible planning - short and long term*

*Feelings and attitudes about chronic illness*

*Special notes on young people in year 9 and older*

*Medical recommendations*

*Further reading*

Available free of charge at [www.tymetrust.org/tymespublications.htm](http://www.tymetrust.org/tymespublications.htm)

See also page 18



# what you think



**Hiya!**

**I thought I'd write you a note to say a HUGE thank you for lending me the 20Q game - it was such fun. A real low energy game and from the minute it arrived my family were enthralled!**

I must admit we beat it a few times but often it was the more obvious thing it couldn't guess. Me and my sister had great fun trying out things we were sure were too obscure but the little thing actually guessed 'Llama'!! He he!

I am, however, thinking of suing the manufacturer [not] because of the Disability Discrimination act - whatever we did it just wouldn't guess 'wheelchair' or 'crutches'! How terrible, eh?



It was rather difficult sometimes working out if what we were thinking of was an animal, vegetable, mineral or 'other'! The only actual 'thing' we could think of for mineral was a rock!

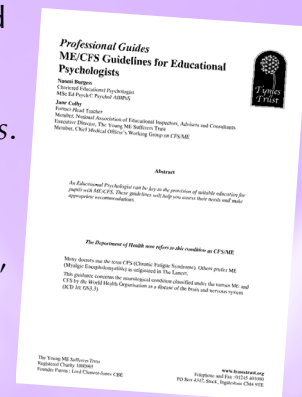
But it did actually amaze us - it's a smart little thing - ok it can't guess everything but when it realised we were thinking of a giraffe or even a llama we couldn't help but laugh. It was great fun catching it out - or trying to - so thanks once again for lending it to us. I think we might end up getting our own sometime as it made us laugh so much.

Our one complaint was its arrogance - it kept telling us we couldn't outsmart it ever - we did! He he! I hope the next family has as much fun as us with the little guy.

Elle Ward  
(and my sister Anne-Marie and mum Nora)

**Why not write and ask to borrow Mark's 20Q game for you and your family to play with?**

I've just read (and printed out), the Tymes Trust's *ME/CFS Guidelines for Educational Psychologists*.



Having 'built a house' from scratch 7 years ago, with our own bare hands, with no prior knowledge or experience of construction work and having had to manoeuvre our way through the minefield of regulations (and originate many too!) I now discover your clear, concise, A - Z step-by-step manual, complete with full-colour illustrations and idiot-proof descriptions!!

Had this fantastic manual been around, when we needed one so badly, it would have made a world of difference not only to how we built our house but it would, undoubtedly, have enabled our house to remain standing today!!

Hope the simile works for you (!) and many, many congratulations on yet another groundbreaking piece of work.

Lynne Kersh

We love to hear from you all with your news, views, artwork and poetry. Don't forget to let us know if you'd like to see them printed in *Vision*.



Thank you for the lovely card. I think you know how pleased

I am with my results. I know how much you do for all of us and it makes things that bit easier.

Love from Elizabeth



I want to really thank you for sending me *Vision*. I was feeling really down but that really cheered me up! Especially Seb's pages. I hope that you like all the stuff I've sent you.

Lots of love,  
Lydia Francis age 12





Mum and I so enjoyed the Friends Reception at Lady Elizabeth Anson's. We found it very helpful and it was greatly appreciated. Thank you!

Anna Linari-Linholm

Xxx

Thank you for inviting me to your get together. Bethany and I enjoyed ourselves and have told the whole class about our extraordinary day out.

I'm lucky to have met such lovely people. We met John Griffin on the way and he told us about his special mountain climb up Kilimanjaro for the Trust.

I'm pleased so many people want to help. Thank you.

Love,

Shannen, Bethany and Lisa



I am sorry you are struggling Jane, but now I do understand why. The Reception was really

educational for Chris and me, and we sympathise with people who have the condition. We so look forward to GP-line working together with you so that we can help one another.

Jeff Reeves

Director, GP Line



Just a little note to thank you again. I enjoyed it all so much and it was a real pleasure to be with you all.

Julia Malin

Elizabeth and I had a lovely time at today's Reception and we were both so pleased to meet you after so long. We felt so fortunate to be invited to Lady Elizabeth's beautiful home and to see the other young people there who are coping so positively with their illness.

We had a few words with the pretty girl with long black hair and her little friend. It must have been a very special day for them. Elizabeth appreciated every minute of it and I think it helped her a great deal to hear about how an adult has led a very successful life in spite of the illness.



Bethany and Shannen

Her frankness about the difficult parts of the illness meant a great deal. Elizabeth's confidence is so much improved at the moment. She wants to teach young children, and on Monday she helped at Charlotte's school as they were holding a special nursery rhyme day. She loved it and the children and the person she was teamed up with thought she was great.

I was particularly glad to meet Jade's Scarrott's mum; she must be so very proud of her. The poems in *Young Hearts* are a real legacy.

Jane Colley

Why not be a Friend of the Trust and join in our next Friends' event? Just go to [www.tymetrust.org/donations.htm](http://www.tymetrust.org/donations.htm) and make a minimum donation of £10. There's a message box where you can enter FRIENDS MEMBERSHIP. Anyone under 18 will need to ask their parents.





# WHAT HAVE YOU BEEN DOING?

## KADIE'S HOLIDAY



Sorry it took so long for Seb to come home. It's because I have been in and out of hospital since we came back off holiday.

I really enjoyed taking Seb on holiday. I hope he enjoyed it too. He loved eating all the Turkish food and swimming in the pool. Seb wrote a diary on holiday which includes photos of him.

He brought a small present back with him, which he wants to put in his office. Thank you for letting Seb come on holiday with me.

Love from Kadie Plumridge



### Tuesday 16th August

Phew what a long flight. I tried to sleep on the plane but there was so much going on. When we got to Turkey it was very hot. The trip to Turunc was stunning, with mountains and narrow roads, and even a few goats. When we got there we went straight to bed. Later on we had dinner - the food was fantastic. We had meatballs! I am going to bed now because all this travelling has made me very sleepy.

Night night,

Love Seb

### Saturday 20th August

Today we caught the ferry to Marmaris. I didn't like it there because there were so many people rushing around and they nearly trampled on me. Later we went to the pool. I love it there just swimming around. Later on we had a well-earned sleep. We had a wonderful dinner down the road. Tomorrow we are resting (I think). Night night.

Love Seb







*Pick a glass, any glass*



*Oopsh*



*Who ate all the bread?*

*Just hanging ...*



## You've all been writing in for Mr Harley's Brilliant Bears ...

Dear Mr Harley

I may appear to be a little 'mature' to be applying for one of your remaining Brilliant Bears, when I tell you I am 31 years old. However, I have been a member since the early 90s and have watched with pride and admiration as your publication has grown. My parents and I all enjoy *Vision* and wish you well for the future.

This is not a selfish request however. You see, my dear teddy bear and best friend, Patrick, has also had ME since he was 9, and has lost his sparkle of late. He has his own bed and needs to rest frequently, usually to coincide with me. He is always there to cuddle and take my frustrations out on when I am having a bad day, so I nominate him for a little reward in the form of your Brilliant Bear. At least then he will have a new companion to inspire him! He is looking a little tatty and worse for wear but is a huge source of comfort, and after 22 years of my severe ME I need all the support I can get.



*Patrick and his Brilliant Bear*

We find *Vision* very positive and upbeat in a way many of the national 'adult' publications are not. I admire your pragmatism and empathy towards, and with, your readers, and wish you every success.

With best personal wishes

Sarah Stokes

*And a bit later ...*

I am sorry, I forgot to include Patrick's address (today is a bad ME day = brain fog. If I had a brain I would be dangerous!)

**... and they ran out!**

So Mr Harley went on a Bear Recruitment Drive in London ... turn over to find out what happened ...

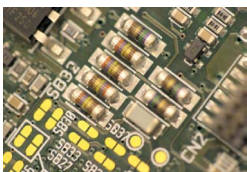
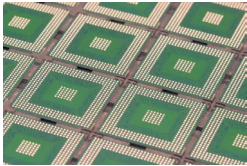
*Seb has found out that his holiday souvenir was actually a UFO (Unidentified Friendly Object).*

*We thought he was just a pretty crystal until he woke up and asked what was for lunch.*

*We asked his name but he said we couldn't pronounce it unless we had three tongues. So we called him Alan.*



# Meet The Team



*Skiing is a serious business*

## Mark Colby

Trust tech support  
[www.tymestrust.org](http://www.tymestrust.org)  
 and now Vision

Age : 35 (mostly)

Work : Motorsport

Sport : Squash

Motorsport can be a high pressure environment. In January 2004 I flew to Florida for a 3 day Le Mans car test (you may have seen a picture in previous magazines). After an hour's sleep I wrote the software for a complete racing gearbox controller while standing in the back of a truck. With no testing at all that code went straight into a 1/4 million pound 200mph racecar (the blue and white one on the left in fact) with the driver's life at stake.

The thing is, I know how to do stuff like that. I've been working with computers for twenty years, from military radars to in-flight telephone exchanges to satellite image processing. I can handle it :-)

It keeps life interesting when we have to deal with things we

really *don't* know how to do. Like lay out a magazine. And apparently someone thought we should make it harder, so ... we haven't done *Vision* in full colour before; if you would like to see how it came out, download the pdf from [www.tymestrust.org](http://www.tymestrust.org). It's about 6MB so I apologise in advance if you don't have broadband!

Q : What's more fun than testing a brand new 1000HP V8?

A : Four people on a squash court ...



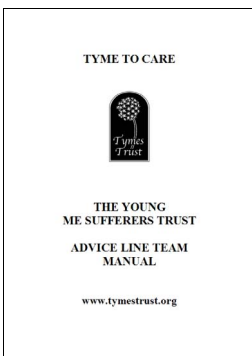
*Please fasten your seatbelts and move tray tables to the upright position*

## Advice Line Team

### *Could this be you?*

Would you enjoy being part of our Advice Line Team? Full information and support are given. It will only take two hours per week of your time and is carried out from your own home through our telephone exchange.

Jane Colley, our newest Advice Line Team member says: 'I do feel that I want to give something back for all the exceptional help that I have had and I know we wouldn't have got to where we are without it.'



Everyone in our Team has personal experience of ME, either through having had it themselves, or through looking after someone who has. That's one reason we receive so many nice messages about the service.

Why not ring 01245 401080 and talk to one of our Team to find out more.

## Thank you Andrea and Fatima

It is really heartwarming when someone who has no day-to-day contact with ME sufferers decides to contribute to the Trust. We have thanked Andrea Foster and Fatima Celestino before for their efforts, and they have been at it again!

Andrea and her daughters ran the Hyde Park 5K in September, and Fatima came to Essex in November for the Billericay 10K. The money they have raised will all go towards the Trust's services for children, as everyone here works for free.

After meeting Fatima at Lady Elizabeth's, Shannen Dabson made a special T-Shirt for her. Thanks Shannen!







## Mr Harley's Bear Recruitment Drive

I have been overwhelmed with requests for my sparkly Brilliant Bears! In fact, I ran out of them! So I went on a Bear Recruitment Drive in London and guess what? I came across a squad of very smart policeman bears (Bobby Bears) awaiting orders.

Fortunately I am very good at assuming authority so I commandeered them.

And so I have sent some of you a Bobby Bear, who I hope very much will keep you company and look after you. They contacted their colleagues and I now have lots - perfect for my Seasonal Gift of Bears.

If you would like a Bobby Bear, just write to me and explain why you would like one.

Best regards

Mr Harley  
Chair of Trustees



*'Ere Sarge, woss that bloke takin' photos for?*

*That's the Chair.*

*Wot? Looks like a bloke to me.*

*The Chair of Trustees you prawn. He's our new Boss. We've been promoted to Seasonal Duties. Stand up straight and tuck yer loop in.*

*Yes Sir. Sarge?*

*What?*

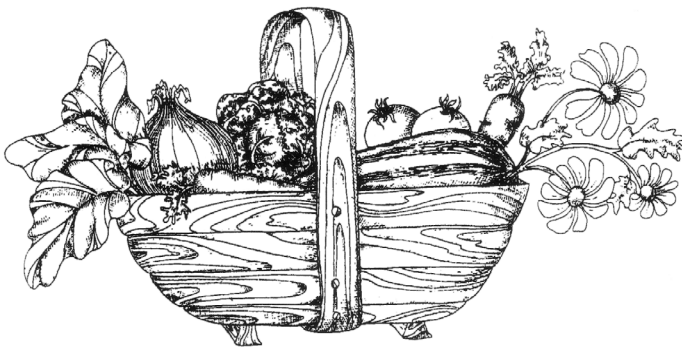
*Can I scratch my nose?*

*Go on then, but try not to be noticed.*

## Insight

We are always being told that fresh food is better than processed. It now seems that fresh vegetables out of season and flown in from abroad, are not as good for us as frozen vegetables.

Sophisticated gas chromatography compared fresh and frozen produce and found higher pesticide residues and high nitrate levels in the fresh ones.



levels of nitrates - as little as 100 times less than the permitted levels. When summer crops are grown in winter, higher nitrate levels are needed to produce growth, so imported fresh vegetables have more residues. They also lose nutrients such as Vitamin C every day they are travelling from faraway places like South America or Africa. Frozen vegetables, on the other hand, are grown in their normal season and processed within four hours of picking, so all their goodness is preserved.'

Their advice was to eat fresh produce in season, rather than, for example, strawberries in winter. You can mix fresh, frozen and tinned produce. And you can save money!

The Austrian Consumers Association commented: 'In many frozen products we could not discover any pesticides and found very low



## Sarah Price

Commercial Manager at JEM Digital

Print, was profiled by *Print Week* magazine.

*What is your favourite piece of print?*

A poetry book we did for the TYMES Trust charity written completely by children with ME.

*Life is?*

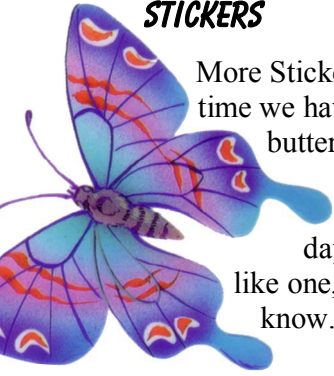
What you make it!

We would like to thank Sarah for the beautiful posters of *Young Hearts*.





**DECORATE YOUR ROOM  
WITH OUR WINDOW  
STICKERS**



More Stickers! This time we have spring butterflies to remind you of warmer days. If you'd like one, let us know.

**Wibbly  
Wobbly  
Web**

I enter a lot of competitions on the internet and I won a Racing Stripes Goody Bag. I thought you could ask for poems and pictures about Africa and give it to the winner.

**Caroline Higson**



Thank you, Caroline! What a good idea. The best poem or picture about Africa will win the Goody Bag and of course there will be a host of runner-up prizes. Or you could take a photo of things that remind you of Africa.

My parents took me to the station to see the station house where he and his family lived. It was amazing to stand where my ancestors had stood decades ago.

**Lucy Player**

Write to us for Lucy's full article, including her Top Tips for finding your ancestors: for example the 1901 census may come in handy to see where they were living at that time. Check out [www.1901census.nationalarchives.gov.uk](http://www.1901census.nationalarchives.gov.uk)

**CLIMBING YOUR FAMILY TREE**



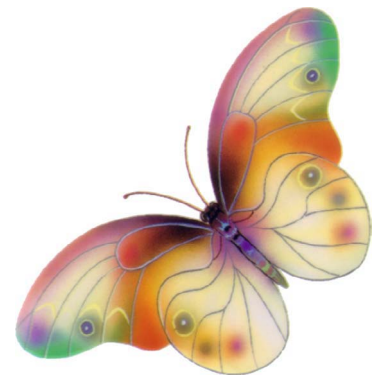
*Winter Fireside*



*I sat beside the fireplace  
And stared into the -----  
I dreamed of throwing ----balls  
And playing winter -----  
I dreamed I built a snow---  
And skated on the ---  
Then mum brought in hot buttered -----  
And that was pretty ----!*

Fill in the gaps. Each dash represents one letter so count them carefully.  
Hint: The 2nd and 4th lines of each verse are supposed to rhyme.  
Prizes waiting for correct answers... and maybe nearly correct ones too?

You may have seen the TV show *Who Do You Think You Are?* That show sparked my new interest - Genealogy - a journey into the unknown without a compass! I can do most of it at home from my sofa. My great great grandad was a station master at Rochford station in Essex in 1932.



**Last Time...**

You sent some great answers to the last poetry competition as well as the ones that were right!

And yes, the answer to the riddle 'What do you get when you cross a sheep with a kangaroo?' was A Woolly Jumper! Well done you guys. No-one guessed the answer to 'What do you get when you cross an elephant with a kangaroo?' It's - wait for it - Great Big Holes all over Australia. Groan.



Write to us at PO Box 4347, Stock, Ingatestone, CM4 9TE

# Should I Call The Doctor?

families whose children have ME often worry whether to call the doctor or not - especially if it's the middle of the night, or Christmas Day!

The trouble is, there are so many symptoms ME can throw at us. It's not just that we don't like to wake the GP up. It's not just that we probably won't get hold of our own doctor out of hours. It's that feeling of 'Is it serious? Can I wait and see if goes away? If it doesn't, should I make an appointment in the morning?'

Almost everyone with ME has found themselves in that situation at some time or another. People naturally don't want to get a name for being an unnecessary bother.

Although things are improving, many of you say that your GP isn't always knowledgeable or helpful about ME. Once, when Dr Nigel Hunt and Jane Colby were invited to address a big London medical conference, they were given the title: 'Does Your Heartsink Patient Have ME?'

And what if you're abroad? You've managed to help your child have a holiday for the first time in years but they're ill. What action should you take?

For some time we've been wondering about a practical solution to this. Our partnership with Nisai Education was set up to help with education. Was there something available in the medical line?



*GP Line Directors  
Chris Arnell and Jeff Reeves*



Now there is. For Young Hearts Day 2005 we are launching our new partnership with GP Line. They have practising GPs to listen and advise, 24 hours a day, 365 days a year, whether you are at home, on holiday – even abroad.

The GP Line membership will be logged in the child's name, since it is the child who is covered for the advice.

A member over 18 could have their own personal membership that follows them to university, college, wherever. The firm is not able to offer the service entirely free, but is very sympathetic to the situation of children and young people with ME and has agreed to a special rate for members of the Trust.

'The point is, these professionals have the time to listen carefully to people's concerns and give the relevant advice, away from the pressurised environment of a surgery.'

Jeff Reeves,  
Director

**for a single, discounted payment of £50 per year, you can speak to a GP whenever you need**

You can call during the day or night, weekdays or weekends - even on Christmas Day - and from on holiday in the UK or abroad. The GP will call you back, so however long the telephone consultation lasts, it will not be on your telephone bill.

*Note: GP Line is not designed as an alternative to normal emergency services. Members should continue to be registered with their local NHS GP. GP Line doctors cannot prescribe drugs. All GP Line's doctors are registered with the General Medical Council and insurance cover is provided by a Medical Defence Union.*

You can take out GP Line cover for one person or for your whole family. GP Line is offering Trust members and associates discounted rates on all their packages:

Single Membership	£50
Single Parent Family	£95
Couple	£95
Family	£135

If you have internet access you can join by clicking through to GP Line from [www.tymestrust.org](http://www.tymestrust.org) and the

discount will be automatic. You will need a credit or debit card, your full address including postcode, and the dates of birth and full names of everyone joining.

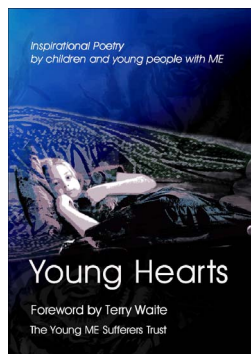
If you have no internet access you can either telephone 0845 2573675 and ask for Sales - remember to ask for the Trust's discounted rates. Alternatively you can send the same personal information and a cheque payable to GP Line Ltd for the subscription required to: GP Line Ltd, GP Line House, 22 The Oaks, Aldwick, West Sussex PO21 3AE.



# The First Young Hearts Day

## Duncan Cox remembers

I shall never forget the day when my wife Lesley and I were privileged to attend the official launch of The Young ME Sufferers Trust publication *Young Hearts* which took place on November 29 at Warwick Castle.



I'm sure many of you will already know that this collection of children's poetry was the inspiration of a 14-year-old ME Sufferer, Jade Louise Scarrott, who was tragically killed in a road accident. The book is dedicated to the memory of Jade and is beautifully presented – we bought 3 copies and I hope they sell many

thousands more. In typical Tymes Trust style, the World Health Organisation classification code for ME even appears alongside the bar code!

Needless to say, with a large photograph of Jade providing the backdrop, this was an extremely poignant occasion. Terry Waite (the former Archbishop of Canterbury's Special Envoy) was the guest speaker launching the book and provided a fitting, and humorous address. Jane Colby (as you would expect) did a superb job of setting the illness in its correct context. Jane also read out letters of support from Prime Minister Tony Blair and Michael Howard.

We were, though, left in awe of the dignity, courage and determination displayed by Jade's mother Karen,

who provided her own very special insight into Jade's short life and struggle with ME.



Watch the TV interview in which Jane Colby explains ME at [www.tymestrust.org](http://www.tymestrust.org)

The event was well attended by the Warwickshire media, but I wish every newspaper editor in the country could have been there, along with every doctor who has so scandalously trivialised this illness, to have heard Karen read out some of the

all too familiar misjudgements made by medical 'professionals' regarding her daughter's illness.

This was, I imagine, a book launch like few others, as the proceedings were brought to a conclusion with *Over the Rainbow* performed by a family friend, after which there was little that could be added.

Since 2004, Terry Waite CBE has become a Patron of the Trust. In his Foreword to *Young Hearts*, Terry says of the children's poems: 'May they bring hope and inspiration to all of us – especially to those who at this time feel the burden of suffering.'

## Remembering Children with ME at home

On 29th November 2005, many of us marked Young Hearts Day quietly in our own homes in tribute to children with ME. It was a day for reflection, for lighting a candle as a symbolic call for research to shed light on ME.

If you are reading about Young Hearts Day for the first time, then why not light your own candle now? Your thoughts are what count. Who knows what power collective thought may have?

Some local and national newspapers have covered the candle-lighting and we hope it will be even bigger in 2006. Send us copies of any stories that you may notice in the press.

Karen Scarrott and her family released 16 red

balloons in New York in memory of Jade. They returned to mark Young Hearts Day in their home town of Warwick.



Jeff and Chris from GP Line enter into the spirit by lighting a candle each to remember children with ME

If you would like to send us photos of your own candle-lighting, whether it was on or after the day itself, we will feature as many as we can in the next issue of *Vision*.

# Volunteers Wanted For Research

## an investigation into Chronic Fatigue Syndrome in children



Dr Gwen Kennedy  
Dr Christine Underwood  
Dr Stephen Greene\*

Professor Jill Belch  
Dr Vance Spence  
Dr Faisal Khan

Vascular Diseases Research Unit  
The Institute of Cardiovascular Disease & \*Maternal and Child Health Sciences  
Ninewells Hospital and Medical School, Dundee, DD1 9SY

### background

Chronic fatigue syndrome (CFS)/Myalgic Encephalomyelitis (ME) is a debilitating condition of unknown cause affecting all age groups but representing a substantial and widespread problem in the young. Recently, using sophisticated techniques, we have demonstrated the novel finding that abnormalities exist in the peripheral microcirculation (small blood vessels) of adult CFS/ME patients. Using recently developed assays we have also found significant differences between adult CFS/ME patients and controls in terms of some of our blood tests linked to blood vessel and inflammatory abnormalities.

CFS/ME research in the UK is under-developed, and for children it is almost non-existent. Estimates vary but there are probably around 20,000 children reported to have CFS/ME in the UK. In a recent report, the UK Chief Medical Officer highlighted the fact that research in children with CFS/ME was an urgent priority. There is some controversy as to whether CFS/ME of childhood is the same as that of adults, in terms of disease mechanism and manifestations.

It is important to know whether these abnormalities, seen in adults, are also present in children as it might be possible to address this with appropriate treatments in the future. We believe that work in this area is crucial, as CFS/ME is becoming one of the commonest causes of long-term school absence in previously fit childhood populations.

### the proposal

We are undertaking a study into children with CFS/ME at Dundee University in Ninewells Hospital. The study would involve a one off visit (of approx 3 hours) to the Vascular Diseases Research Unit, where we would carry out a set of investigations in children with CFS/ME and healthy controls. These investigations have been successfully carried out in adults and will be repeated this time in children.

The investigations include a medical history, a thorough clinical examination, completing a couple of

questionnaires including quality of life questionnaires, a blood sample (for various blood vessel & inflammation research measurements, which is approximately 3 tablespoons worth) and the activity of the small blood vessels which will be tested on the skin of the forearm. Apart from the blood test all tests are non-invasive.

### volunteers

We need to recruit 25 children with CFS/ME (aged between 9 and 18 years) and 25 healthy children who do not have Chronic Fatigue Syndrome to help us in our research in this condition (aged between 9 and 18 years).

### what you can do

If you are aged between 9 and 18 years, or if you have a child with CFS/ME in that age group, and you may be interested in participating in this unique opportunity please send for and complete the form and return it to us. We will be in contact with you thereafter.

Because our tests are novel we require healthy children to also be recruited to enable us to compare the test results. If you or your child can think of any healthy child between 9 and 18 who would be willing to have the same tests we would be grateful for their contact details. This may be a friend, classmate, cousin, brother or sister etc.

Any costs (e.g. petrol, bus or train fares etc) incurred travelling to the hospital for a study visit will be reimbursed to any participants and their parent/guardian. If you are travelling a distance we can organise overnight accommodation, which you will again be reimbursed for.

### next steps

To obtain a form to complete, send to The Young ME Sufferers Trust.

Return the completed form directly to Dr Gwen Kennedy at Ninewells Hospital.





**The Ninewells research is the first biomedical study into children with ME. It is being funded by The Young ME Sufferers Trust and MERGE, of which Dr Vance Spence is the Director, with a contribution from Search ME.**

*How widespread is ME in children, and what effect is it having in schools?*

In 1997, the largest study of ME ever to be carried out was published in the *Journal of Chronic Fatigue Syndrome*. The researchers were Dr Elizabeth Dowsett and Jane Colby, who had studied a school roll of 27,327 staff and 333,024 pupils over a period of 5 years.

The study showed that ME is the biggest cause of long-term sickness absence in schools. In children, the percentage was 51%, far in excess of any other condition. There was whirlwind coverage in the media and *The Guardian* ran it on their front page under the headline *Schools Hit by ME Plague*. The study was featured on all the main news channels and on *Today with Adam Boulton*.

This diagnosis was significantly associated with case clustering. The average prevalence of ME was found to be 70 per 100,000 in children and 500 per 100,000 in staff. But due to the clustering pattern observed, averages are misleading. In one cluster, the prevalence in children calculates to 710 per 100,000 and in staff, to 5454 per 100,000.

The researchers found that home tuition was more generously provided in psychiatric/psychological illness and musculo-skeletal conditions than for ME. This was ironic, considering how often ME has been treated as if it were itself a psychological condition. A double standard was operating.

Since then, many government documents have recognised pupils with ME as requiring proper support. In spite of this, appropriate provision has been patchy, depending on the area. The Trust has campaigned, run courses, and produced a bank of literature for professionals to help inform and educate.

There is no substitute for biomedical research to show up the physical effects of ME in children, both to validate their illness and to find out what can be done. The Trust welcomes the start of this groundbreaking study by Dr Kennedy and her colleagues.



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



## **GP magazine covers ME in children and young people**

*From a letter published on 11 November 2005*

CFS/ME [...] differs in classification and in cause from 'chronic fatigue'. As your headline correctly highlighted, patients with fatigue of depressive origin may benefit from exercise, but those with CFS/ME are typically made worse. This is often diagnostic. Patients may be extremely ill during the first stage, when symptomatic support and physical aids are recommended. We recommend supported self-pacing during the long stabilisation phase [...] If Cognitive Behaviour Therapy (CBT) and / or Graded Exercise Therapy (GET) are undertaken at any stage, even when symptoms abate and strength returns, the therapist should not assume the absence of physical

abnormalities or limitations, as there is a risk of iatrogenic\* injury.

Dr Nigel Hunt

Essex GP

Associate Director of Post Graduate GP Education for the Eastern Deanery

Jane Colby

Executive Director

The Young ME Sufferers Trust

\*'iatrogenic injury' means injury caused by a physician.

*This letter was a follow-up to a full-length feature by Dr Hunt and Jane Colby, also published in GP magazine, about CFS/ME and 'chronic fatigue'. See The Brief page iii.*

*Dr Nigel Hunt*



# Stamina And Examinations

in this excerpt from **ME/CFS Guidelines for Educational Psychologists**, Educational Psychologist Naomi Burgess and former headteacher Jane Colby advise professionals

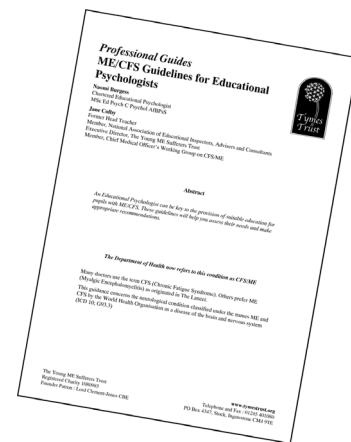
A child with ME/CFS can become exhausted quickly, with resulting malaise and possibly relapse. This can mean that tasks undertaken in school, school tests, or national examinations will be subject to falls in performance between the beginning and end of a task. Considering how best for the student to take examinations, it is advisable to ask for rest-breaks rather than simply a block of extra time at the end. It may be necessary to ask for both. Other related considerations are:

- A potential need to allow snacking during an examination to avoid a drop in blood sugar making the child ill.
- A potential need to reschedule the start time, since ME/CFS patients typically have a best and a worst time of day.
- A potential need to use the home as the venue for the examination, to maximise the effort that can be used on working rather than travelling; the aim of special arrangements is to level the playing field as much as possible for those who are disadvantaged, so that they may display their best work.
- Whether you need to apply for consideration of coursework marking, especially as a low coursework grade can put a ceiling on examination marks.
- Whether or not their examination preparation is disrupted by illness.
- Performance and health may be affected for an extended period (days or even weeks) after an examination.

## points to be aware of

- Some schools separate the task of organising Special Arrangements from that of Special Considerations, so please be careful that this is considered from the outset.
- Requests for consideration regarding coursework marking must be made at the time or within a very small amount of time following the submission of the work.

The Guidance from the Joint Council regarding examinations changed substantially in 2005 so please ensure that you are aware of what the school can now do, and is proposing to do.



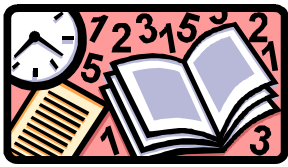
- It may be advisable that SATs are not taken, in order to avoid disruption to the child's recovery and thus to the possibility of success in examinations conferring qualifications, which should receive priority.
- It may be advisable to avoid mock examinations and have some simple practice sessions that are not so demanding on time or energy, as mocks can disrupt recovery and militate against achievement.

## medical recommendations

It is important to remember that a General Practitioner is a qualified doctor who diagnoses and treats medical conditions and a recommendation from a General Practitioner to reduce demand on the child - for example, a suggestion that teaching in the home should be considered - is as valid as one from a consultant paediatrician. The exemplar *Megan's Journey* shows home tuition and other modifications being granted by the LEA upon the request of Megan's GP. Government statutory guidance *Access to Education for children and young people with medical needs* states that obtaining a recommendation from a paediatrician is desirable, but this is not a statutory requirement. It cannot be, since provision must be made for children unable to attend school once three school weeks have elapsed. An appointment with a paediatrician is normally only available this quickly in emergency situations. It may therefore constitute a breach of statutory obligations to wait for a paediatrician's recommendation.

**ME/CFS Guidelines for Educational Psychologists is at [www.tymetrust.org/tymespublications.htm](http://www.tymetrust.org/tymespublications.htm)**





# You Tell Us - Exams

Jane,

We met in 2001 at a seminar you ran in London on the education of youngsters with ME. Thanks to the advice I gleaned at your seminar my daughter managed to take 5 GCSEs up to age 18, so I am grateful to you for that.

Sue Waddle (who runs Have a Cuppa for ME)

Elizabeth has got A stars in History, French and German, and A's in the other four -Latin, Maths, Chemistry and Biology! She met the goal she set for herself.

Thanks for all your help along the way.

Jane Colley



## And beyond school...

Kirsty achieved her first GCSE – ITC grade C – in 2002, when she was 14. We had a staggered educational plan working towards GCSEs one or two at a time, but she suffered a bad relapse in March 2003.

She had 18 months total convalescence from the age of 14 and a half to 16 with no education and no goals or targets to reach, just rest and relaxation. She recovered very significantly, went to our local college and discovered sign language - a continuous assessment course of 2 hours per week including a 15 minute break.

Kirsty successfully completed Entry Level and Entry Level 1 and starts Level 2 this September. Through the government's scheme to help disabled people into work, she has also started employment in BHS for one and half hours per week split over 3 afternoons.

Carol Watts

We would like you to celebrate with us! Our 14 year old daughter received ALL the exam concessions we requested for her first GCSE exam! The examination officers both here and in the UK have been exceptionally accommodating and understanding - we are infinitely grateful.

I believe it is due to the excellent work Tymes Trust has been doing that more and more educationalists are beginning to understand, and have compassion with children afflicted by this illness.

This praise is sincere ... we used your documents to put an 'information pack' together for my daughter's distance learning college.

With joy and gratitude!

A mother from South Africa

## Quotes we like:

If at first you do succeed,  
Try not to look too astonished.

Take pride - in how far you've come,  
Have faith - in how far you can go.

Eleanor Ward

It's Jack Granby. Just thought I'd let you know that I have my A level results.....

A in General Studies A in English and A in Sociology (including full marks in the religion module and the crime and deviance module). The *Basildon Echo* featured a picture of me on the front and ran a piece about how I passed my exams in spite of having ME.

Best wishes

Jack



# SEB'S MANOR

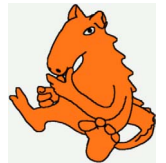
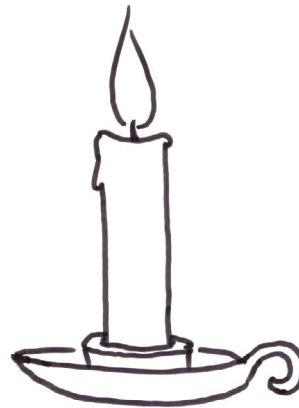


## CANDLES TO COLOUR

Especially for my page, the Steering Group for the PRIME

Project (patients, carers and researchers) drew you these candles for Young Hearts Day. They couldn't light a candle as the fire alarms would have gone off and the whole building would have been evacuated! Imagine that, in frosty London. Brrrr ...

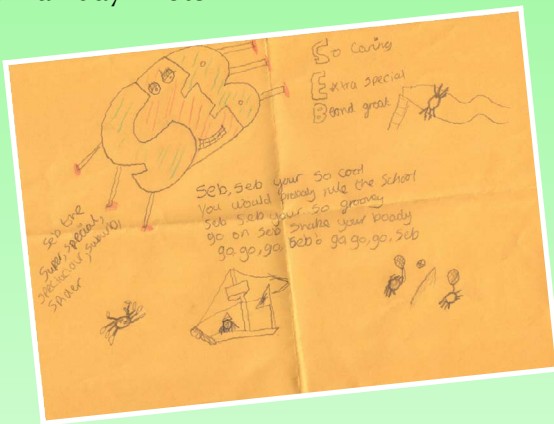
Find PRIME at [www.prime-cfs.org](http://www.prime-cfs.org)



'Boo'

## Sebastian Says

While I was on an extended holiday with Kadie, Jodie Halliday wrote in.



How could she know all this about me? I am exactly as she has described me! I sent her one of my bendy men from my Treasure Chest, because she has shown me the proper respect due to a Super-Spider.

*So caring*

*Extra special*

*Beyond great*

*Seb the super, special, spectacular, superb spider!*

*Seb, Seb you're so cool*

*You would probably rule the school*

*Seb Seb you're so groovy*

*Go on Seb, shake your body*

*Go, go, go, Seb, go go go Seb!*



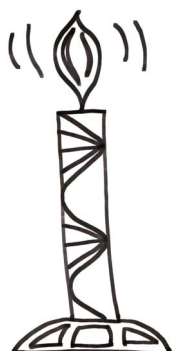
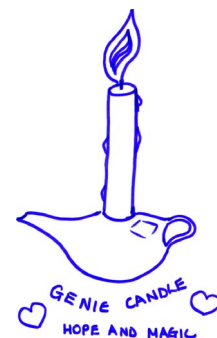
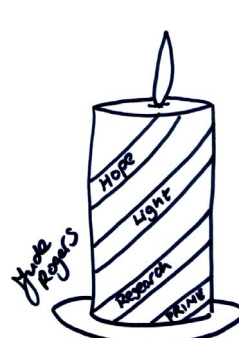
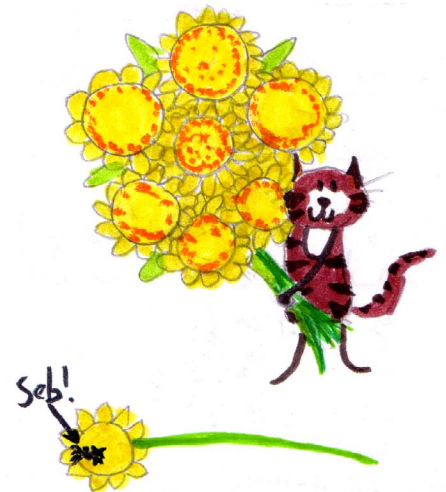
## Hi Seb!

Here's a little pic to help give you sunshine with sunflowers! Love from Lydia Francis

XoXoXoXoX

PS There is a little black spider crawling on my window – any relation?

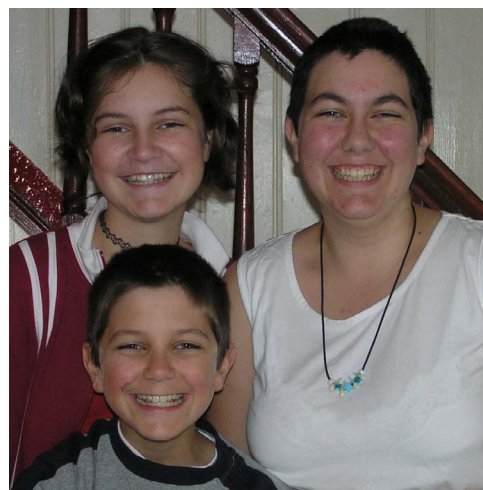
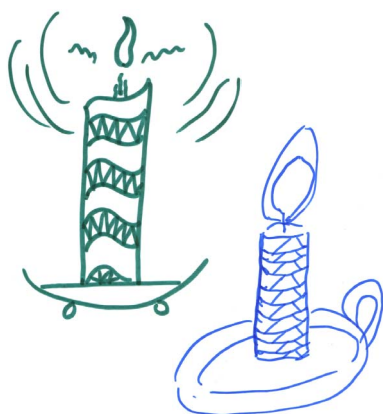
*I think your little black spider visitor was my cousin Sinbad who can make himself very small by magic! He is always travelling around.*



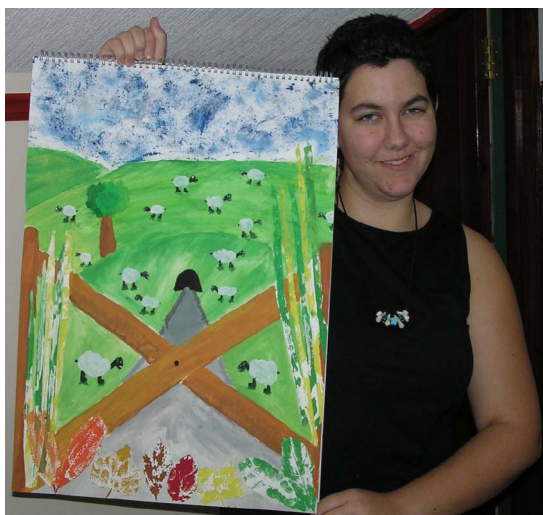




Candle Fatigue Syndrome



Would you like to be in my new photospot? Katie Evans is very artistic. (And so am I. I do most things well, when I come to think about it. And I am SOOO modest.)



'My name's Katie Anne. I'm fifteen nearly sixteen and I've had ME for over two years.'

'My younger sister Julie (13) and my little brother Alun (11) both suffer with it too, in a different way.'

'For me the hardest thing is to express feelings, so I write them down, mostly in poems. I've written thirteen and some have been published. I write poems in the middle of the night and never remember doing it. I have to write everything down so I don't forget - everyone keeps reminding me of everything.'


'What was I saying?'

'My friends, they don't understand. I don't expect them to. I'm different now. Everything's different.'

'I know there are good things that have come from my ME, even if they are harder to see sometimes, like making new friends and writing to them. Knowing there are other people like you who understand.'

## SEB'S COMP

Great news. Simon Selkin is now Santa Selkin. He's sent me TWO HUGE BOXES of magic pens. And I have lots of new secrets in my Treasure Chest.

 To win something (your family can help) count how many times I appear like this in this issue of *Vision*. Get counting, and remember I might be hiding ...

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

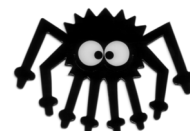
Send to : Seb's Comp, PO Box 4347, Stock, Essex, CM4 9TE



*Katie Anne.*



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



# A letter from ...

Hello, I'm Craig and I am 16 years old.



I have suffered with ME for about 6 years now and I thought I'd tell you how I learnt to cope with my condition.

I was first diagnosed in 1999 although I had been feeling unwell for a few months beforehand. As a 9 year old it is pretty difficult to understand the illness; also as a child you don't really listen to what your body is telling you.

For the first year or so I used to fight, not only against my parents, but also my own body and feelings. At first nobody, including myself, my parents and my sister understood what ME was. All I knew was that I was suddenly different to everyone else and had no energy to do anything. For the first year I spent most of my time on the sofa. After my mum had researched about ME and had got in contact with Tymes Trust we learnt that in order to get better I had to pace myself.

I was pulled out of school completely in 2000/2001 and was home tutored. I never went to lessons at my secondary school as I could not cope with the demands. I was taught 5 subjects by 5 different tutors for 1 hour per lesson. Although this is not easy, I was able to pace myself and organise my days around these one hour lessons.

## Sparkly Letters ...

Reading the poetry in *Vision*, by sufferers even younger than myself, has been a real encouragement to me during the months that I have been housebound. Many thanks to all your truly inspirational members who have had the courage to share their experiences – it means a lot!

I would love to receive *Young Hearts* to read more about the experiences of the incredible young people that have contributed. It really is good to know that I'm not alone.

Sarah R Gilligan

PS The sparkly bears are a fantastic idea. They made me laugh when I heard about them. How's that for giving someone back their sparkle?!



After 4 years of tutoring I passed my GCSE's with 3 A's, 1 B and 2 C's. It just goes to show that even though it seems like ME has completely destroyed your education, with a right mix of work and rest it can be possible to achieve what you want.

I am now currently doing a full-time IT course at College. I am able to do this by coming home and immediately resting. I listen to my body and I can feel when the time is right to rest. I do 20 hours a week at college and I have felt no adverse effects so far!

My advice to anyone suffering with ME is not to give up. One of the things I have learnt with ME is that you have to listen to yourself, only you know when to pull back and you know when you are ready to try again. ME brings a lot of responsibility to its sufferers. Once you have learnt how to tame the ME then you can begin to progress, just like I have.

Craig Marshall

We send all our love to those whose ME is extremely severe. We know that while your body is so weak, you are probably unable to do any work or follow any pastimes. If you are confined to bed at the moment and your parents would like to send us a photo or a message from you, we would love to feature you on these pages so that everyone can remember you in their thoughts.



A friend should be caring  
understanding and true  
respectful and loyal  
As you would want  
them to be to you

Jade Scarrott

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

Emma Gray



*Evenin' all*





firedance

flames burst into  
indigo skies  
raging as high as  
every bird flies.

darkness falls  
and the fire weakens, but  
never snuffed out,  
colours fade, almost cease.

even though  
it is almost gone,  
once again  
it will dance for you!

Lydia Francis

**THROUGH TIME**

**Stuck in a capsule, trying to break the glass,  
Bullied by a clock; it's going way too fast.  
It seems I'm barely moving, the world is whizzing by,  
But I'm travelling, still travelling, travelling through time.**

**My head keeps twisting round; how can I forget,  
All the joys that were battered by pain and regret.  
It seems I keep on losing, but I'll leave it all behind,  
'Cos I'm travelling, still travelling, travelling through time.**

**Moving through the dark now not knowing what's ahead,  
Feeling so exhausted but I cannot find a bed.  
It seems like I was falling, but in arms of love I find  
That I'm travelling, still travelling, travelling through time.**

**It seems like I am wasting, bones are on the grind,  
But a light is now burning through the edges of my mind.  
In just a day a thousand years will shine,  
For with you I am travelling eternally through time.**

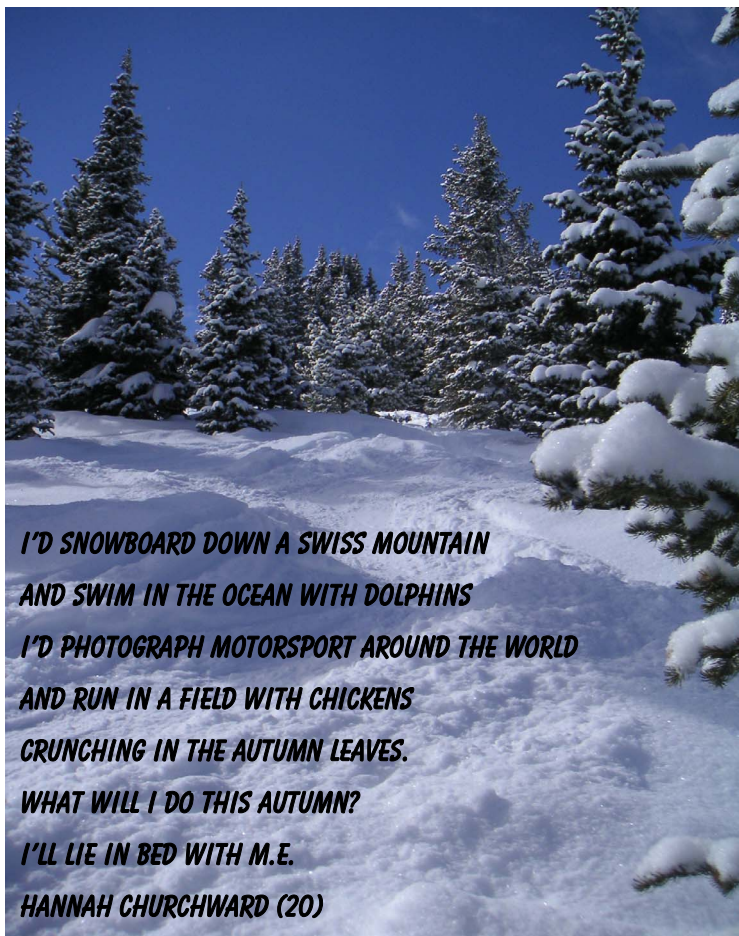
**Robin Sansom**



# On a Postcard

## The Shirley Conran Writing Competition

Prizewinners!



**I'D SNOWBOARD DOWN A SWISS MOUNTAIN  
AND SWIM IN THE OCEAN WITH DOLPHINS  
I'D PHOTOGRAPH MOTORSPORT AROUND THE WORLD  
AND RUN IN A FIELD WITH CHICKENS  
CRUNCHING IN THE AUTUMN LEAVES.  
WHAT WILL I DO THIS AUTUMN?  
I'LL LIE IN BED WITH M.E.  
HANNAH CHURCHWARD (20)**

What I would like to do this AUTUMN.....

*I would like to start to learn  
how to drive, and earn  
some independence.  
Instead of watching from over a fence  
I would like to be in the driving seat.  
That would be a great feat.*

*Jane Fawcett (18)*

*I want to walk in Cullen Grounds and  
breathe the crisp, frosty air*

*I want to pick the biggest apples and  
throw the rotten ones at my sister!*

*But I will have to be wheeled for two  
minutes and then back inside.*

*I will keep my smile because I know that  
one day I will do all these things my way.*

*Lydia Francis (13) (excerpt)*

## art exhibition

*supported by The Young ME Sufferers Trust*

The exhibition of photographic artwork by children and young people aged 15 to 20 at the Washington Gallery in Wales was a great success.



*Photographer Suzanne Greenslade and Jane Colby*

Artists : Amanda Williams, Calvin Williams, Dominic Burn, Michelle Penny, Catrin Greenslade, Femmy Rees-Rowlands



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