

The Young ME Sufferers Trust

2007-1

£2-95

# Vision

for young people, families and professionals

## **BYRON HYDE MD**

Talks about the first  
testable ME Definition

## **WHY CFS IS NOT ME**

Our submission to NICE

## **'SCHOOLS SWEEP BY ME PLAGUE'**

10th anniversary of  
Dowsett and Colby  
schools study

## **THE BRIEF**

Protecting Children  
Nightingale ME Definition  
Special Educational Needs



View in full colour at [www.tymestrust.org](http://www.tymestrust.org)

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## THE YOUNG ME SUFFERERS TRUST

*Registered Charity Number 1080985*

Founder Patron	Lord Clement-Jones CBE
Patrons	Earl Howe Barbara Windsor Shirley Conran Terry Waite The Countess of Mar
Friends Patron	Lady Elizabeth Anson
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*Cover : 'This T Shirt doesn't mean I  
have to run a marathon does it?'*

# Our Patrons



Lord Clement-  
Jones CBE



Earl Howe



Shirley Conran  
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Lady Elizabeth  
Anson



The Countess  
of Mar

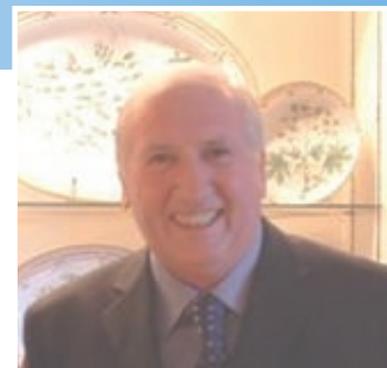


Barbara Windsor  
MBE



Terry Waite  
CBE

# Vision - The Project



*Keith Harley*

Every Spring brings new initiatives and this year is no exception. The new Learning Commitment Awards are now being presented to recognise the success of young people with ME who have been using the virtual learning methods we have pioneered with Nisai Education, who have recently appointed their own specially trained teachers. The Awards are - naturally - being presented online!



Given the right educational support, young people with ME have great potential but all too often the traditional system fails them.

Our Founder Patron Lord Clement-Jones is hosting an afternoon tea in the House of Lords to celebrate our young students' efforts.



We are also launching the second generation Tymes Trustcard, endorsed by the Association of School and College Leaders. Tymes Trust Young Advocate Shannen Dabson will be at the House of Lords to receive the first of these Trustcards. If you have an old-style card you do not need to change it until it expires. If you have never applied, this is your opportunity to get a new one. Just contact us for an application form. It comes with a redesigned information pack.

Another encouraging development is joint work, in particular with the ME Association. Our Executive Director Jane Colby led a telephone training conference for the 'ME Connect' staff, produced a new leaflet for the MEA on ME in children, and contributed a double-page spread to *ME Essential*.



Chair of the MEA Neil Riley emailed Jane: 'Hilary and the ME Connect team were impressed by the scope of knowledge that you have and I would like to build a close alliance to our mutual benefit.' I second that.

A statement has also been produced by eight ME organisations including ourselves, on the draft guideline for the treatment of ME/CFS by the National Institute for Clinical Excellence.

Our statement agrees with NICE that doctors need guidance on the diagnosis and management of ME/CFS, that patients must be involved in decisions on their own care, and that 'the principles of informed consent are paramount'.

However, the NICE draft guideline recommends cognitive behaviour therapy (CBT) and graded exercise therapy (GET) as the treatments of first choice for ME/CFS when, as our statement says, 'neither can be justified for all patients on the research evidence' and 'there is patient evidence that GET has the potential to cause damage, and [...] that CBT [...] can have adverse effects. The guideline has so widened the definition of ME/CFS as to include almost anyone with chronic unexplained fatigue'.

Tymes Trust also produced an individual response to NICE explaining why ME is different from CFS. In this response, we quoted from the new Nightingale Definition of ME by Dr Byron Hyde of the Nightingale Research Foundation. This definition clearly separates ME from CFS and we were very pleased that our Executive Director was asked by Dr Hyde to assist in editing it. We have gone into some detail about this for you, including excerpts on page ii of *The Brief*.

I am also delighted to report that many of my LeBlanc bears have now found good homes amongst our members.

Kind regards

Keith Harley  
Chair of Trustees





As Founder Patron of the Trust, I am looking forward to hosting an afternoon reception in the House of Lords on Wednesday 28 March. We are recognizing the excellent educational results obtained by the

Trust's young members and others on Nisai Virtual Academy courses, following the online presentation of the first Nisai Education/Tymes Trust Learning Commitment Awards. The successful Tymes Trustcard scheme is also being expanded with the launch of a second-generation card and a new information pack.

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



We all have a shared responsibility for our shared future. Individuals, families, government, business, and voluntary organisations all have a vital role to play. Organisations such as the Tymes Trust show how such principles can be put into practice. The Trust provides invaluable support to children and young people with ME, and to their families, and has also helped to raise awareness of ME issues.

I know that many have volunteered their time and money to make this happen, and I would like to congratulate the Trust for all it has achieved and for the difference you have made to so many lives.

I am sure you will continue to go from strength to strength.

**The Rt Hon David Cameron MP**  
**Leader of the Opposition**

## Online Petition

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

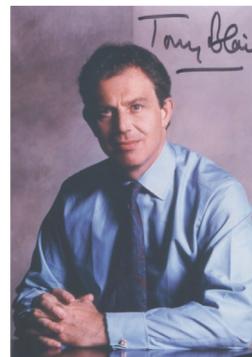
Konstanze Allsopp, a long-term ME sufferer, wrote to us: 'I have gone through the entire scope of disbelief, difficulties in getting benefits [...] I decided that there is one way to make my voice count. My husband and I have started a petition to the Prime Minister[on the Downing Street website]. It may only be a small thing but over 200,000 patients, their families and carers DO have a voice.'

***'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.'***

*Submitted by Konstanze Allsopp*  
*Deadline to sign up by: 22 January 2008*  
*Signatures to date: 3400*

On 20 July 2004, Dr Stephen Ladyman, then Secretary of State for Health, was asked by Paul Burstow MP about the implications for current NHS practice of the World Health Organisation's classification of myalgic encephalomyelitis/chronic fatigue syndrome as a neurological disorder.

Dr Ladyman explained that The World Health Organisation's international classification of diseases,



The Tymes Trust is a respected national voluntary charity offering a friendly, personalised service for children and young people with ME and their families. It is committed to providing continued and expanding high quality services,

whilst maintaining a long established personal approach, specialising in providing practical solutions to problems.

**Prime Minister Tony Blair**

ICD 10, provides a system of categories for international systematic recording. He said: 'They are not diagnostic criteria and are not used by clinicians as such' and that 'services have not been designed around the ICD 10 in the past, nor do we expect them to be in the future.'

You or your family may wish to sign Konstanze's petition.

# In The Spotlight

tenth anniversary of dowsett-colby study

**SCHOOLS SWEEP  
BY ME PLAGUE**  
Illness blamed for 51pc  
of long-term absence

*The Guardian*  
Front page leader  
22nd May 1997

**This year is the 10th anniversary of the 5-year Dowsett/Colby schools study†**, still the largest ME study worldwide, which took the UK press and media by storm.

For the first time the medical establishment and society as a whole had to confront the possibility that ME in children not only existed, but that it was the largest cause of long term sickness absence from school - 51%. It was also the largest cause of such absence in school staff.

The media furore sparked wider medical interest. ME in children has since become a mainstream concern but incorrect beliefs about the psychology of ME have bedevilled children's treatment and education. This has been, and still is, the focus of much of the Trust's family support work and campaigning, with ME being classified as a neurological illness by the World Health Organisation.

When asked how the study came about, Jane explained: 'As a child, I read many Once Upon a Time stories, and even began one of the chapters of my book *ME - The New Plague* that way. Well, this is like a true Once Upon A Time.

'In 1985 I caught a virus related to polio and developed one of the severest cases of ME ever to be diagnosed by Dr Betty Dowsett, the UK physician with the largest database of ME patients over more than 30 years. A giant in the field, she was the source of all my original knowledge of ME. Dr Byron Hyde acknowledges her in the *Nightingale ME Definition*. They are both members of the Newcastle Research Group, which should be commended for preserving and continuing to develop the real knowledge of ME in the UK.

'When I was starting to get a little stronger - having left my profession as a head teacher to rebuild my health - Dr Dowsett said to me, "The trouble is, we don't know the pattern of what's happening in schools."

'"Let's find out then," I replied. It sounds simple but it took us five years. The rest you probably know. That day was a milestone.'

† *Long Term Sickness Absence due to ME/CFS in UK schools; An epidemiological study with medical and educational implications*

Dowsett EG, Colby J  
*Journal of Chronic Fatigue Syndrome* May 1997 vol 3 (2)  
pp 29-42

## Tonight With Adam Boulton Sky News 22 May 1997

**Adam** *It's been called ME, now it's officially CFS - Chronic Fatigue Syndrome.*

*According to a report today, it now accounts for over half the days missed through sickness by schoolchildren. The victims are absent from class for prolonged periods, sometimes stretching to years, and their supporters are demanding an increase in special tuition. [...]*

*Some doctors are still sceptical that it's an illness at all. There are no tests to prove its physical existence, other than the personal testimony of sufferers. [...] Is there a dangerous new illness in need of more resources to tackle it, or not?*

*Joining me tonight are Jane Colby, who helped compile today's report, and she's the author of *ME - The New Plague*, Dr Tony Clere from Kings College Hospital in London and the psychotherapist Peter Bull, who's treated many ME sufferers. Welcome to you all.*

*Jane Colby, your suggestion is that this is a definable illness and the people you are talking about all have the same problem?*

**Jane** *The illness I'm talking about is basically a neurological illness. We know that if you talk about chronic fatigue, that's an enormous number of people. Within those you have got sub-groups, and if you're talking about the actual neurological disease of ME, then you've got to find a suitable name. Chronic Fatigue Syndrome is a confusing one.*



*The ME Association has produced a new leaflet on ME in children, authored by Jane Colby, price £1. 'ME Essential' Issue No 102 carries a double-page spread, also by Jane.*

# what you think



**I wanted to thank you** for giving myself, and my daughters Chloe and Jess such enormous support.

I've watched the Invest In ME conference and found it really heartening to hear how hard people are working to further our cause.

Good Luck and Best Wishes for 2007  
Liz, Chloe and Jessica  
Harrington

**Could you please send Darren an application form** for the National Listening Library. Thanks for a great magazine and the great work carried out for ME sufferers like Darren. He is looking forward to books from the Listening Library.

Roger Jenkins



I wanted to thank you for giving myself, Chloe and Jess such enormous support. I've watched the Invest in ME conference & found it really heartening to hear how hard people are working to further our cause. Good luck & Best wishes for 2007, Liz & Chloe & Jessica

**Thanks! My daughter got a grade B art GCSE and GCSE equivalent qualifications (adult lit & adult num) thanks to your advice.'**

*Free publications on the education of children and young people with ME are at [www.tymestrust.org/tymespublications.htm](http://www.tymestrust.org/tymespublications.htm)*

**Regarding the reception in the House of Lords,** I regret to say that I am just too unwell to travel so far, but I do appreciate the invitation and I hope the event is a great success. I have to say that the on-line learning project and the Tymes Trustcard are both brilliant ideas.

Best wishes  
John Simpson

**On the Trust's submission to NICE**

Well done Jane and The Young ME Sufferers Trust :-)  
Duncan, Warwickshire Network for ME

Absolutely excellent.  
Jacqui Footman

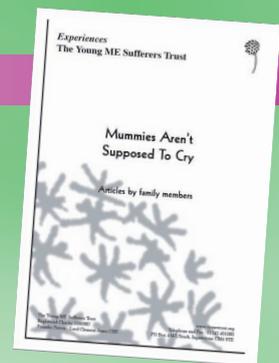
Well done! An excellent submission.  
Peter Ruberry, Sub-Editor, Shropshire and Wrekin ME Support



*the new Nightingale ME Definition)*

**It has made me very happy** reading this. And I wasn't at all happy the day it arrived!

Dr Betty Dowsett  
(after reading



**I just wanted to say how much I appreciated Mummies Aren't Supposed to Cry - the Articles by Family Members.** It really does underscore how ME affects the whole family. My daughter has had ME since she was seven and Christmas in particular can be such a hard time. Glenys Thomas's articles struck so many chords ... how often I've been at the kitchen sink with tears flowing but also had support and cheer from dear friends and unexpected quarters... how you can feel reduced to behaving quite unassertively by professional encounters ... the juggling because you have other children who need your time and support ... the frustrations and isolation, the guilt because sometimes you have to go out to shop or collect your other children but you have no-one to sit with her ... the shared disappointment whenever there's a relapse ... the sense of a lost childhood.

'Mummy sometimes you must just let me be sad for a bit.' How profound. Just wanted to say thank you for another perspective and for all your work in general.

Jill X

**After talking to one of your lovely Advice Line ladies** on Monday, I thought it would be really helpful to all of us out here who have young children with ME (by this I mean the pre-teen years) if it could be made clear that outbursts of anger, tears and even screaming for trivial reasons are normal with ME. My daughter has suffered with this for the past 4 years, and my 8 year old (yet to be diagnosed - fingers crossed it won't be ME) is suffering at the moment. We have 2 other kids at our primary school with ME and parents say the same thing happens to their children. GPs don't seem to have any knowledge of this symptom.

After the outburst has happened, often lasting 30 minutes or more, they carry on as if nothing has happened and seem to completely forget about the incidences. It would help all us parents to feel it's not just our family going through this.

Gillian on the phone said to me that a 6 year old's school was telling his mum that he had behaviour problems when she knew that wasn't the case. I'm sure it's down to the brain dysfunction when they

are really tired. Hope this can be of some help to other people on your phone lines who have this problem with their children.

Another important point to make is how frightening it is to brothers and sisters when it occurs. It has to be said that they are the ones who quite often cause the ME sufferer to lose their temper, because again the age of the siblings is often very young and they have no idea how ME affects their brothers or sisters. Often in our experience they have a shock when they've been on the receiving end, just because the ill child suddenly can't take anymore. Thank you.

Sharon Cox

*Sharon is correct that emotional lability (mood changes) are common in ME because of effects on the brain. Weepiness is often the first sign of exhaustion. Rest should be taken straight away before the young person becomes worse.*

*See the Quick Tour of ME and Tymes Trust Services at the top of our publications page [www.tymestrust.org/tymespublications.htm](http://www.tymestrust.org/tymespublications.htm)*



**We were so pleased to see so many of our pictures** featured in Vision. I

enclose a small sum of money and would ask if you have a spare copy or two, then please may we have them?

With warmest regards,  
S Kimberley

*We still have spares from most magazine print runs so if you want any, just send us the cover price (P&P is included).*

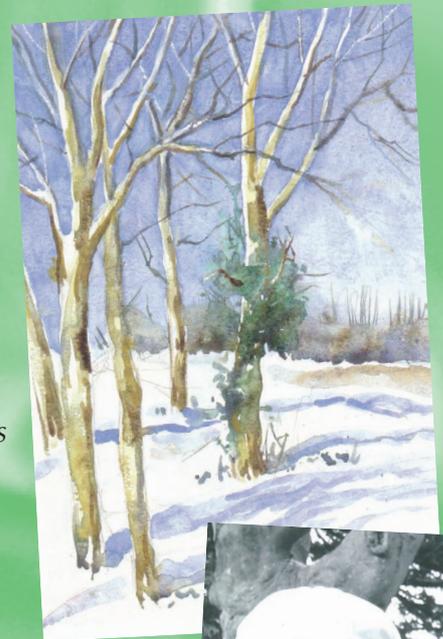


**Loved your speech** to the Invest-in-ME Westminster conference. Watched it on DVD.

Eilidh Hewitt

*The conference DVD with Jane's lecture is available from [www.investinme.org](http://www.investinme.org)*

*Water colour by Tymes Trust member Andrew Hewitt, which was printed as a greetings card.*



**Thank you for my Mini-Vision :)** I think it's a really good idea to do a miniature version as well! I was emailing to ask if I could have one of your LeBlanc bears for a friend of mine who also has ME. She has it very severely and I haven't heard from her in a while but feel sure that she'd like one of your lovely bears to cheer her up.

Kat xXx

*We sent one of course!*

# WHAT HAVE YOU BEEN DOING?

Dear Mr Harley,

I was so pleased when one of your gorgeous bears arrived on our doorstep. He looked cold so I immediately scooped him into my arms and gave him a great big cuddle!

His full name is Sugar Snowy Frost Cuddles Shivers Chilly Le Blanc Halstead (Sugar for short).

At the moment he is sleeping through this cold day - I thought polar bears loved the cold?

His best friends are two of my bears from Jersey

(Frostie and Icing Sugar) who speak French. Sugar is very pleased as noone else can speak French except a jet-black panther called Sooty who is well educated.

When he arrived it really made my day. Thank you so much. It is very kind of you.

I enclose a picture



of Sugar and me on our first of many outings.

Love Chloe Halstead (age 14, young at heart)

Please find enclosed a donation for £35 and a prototype handmade gift card I made myself. I sold these cards at work to raise money for the charity and I only have the prototype left! So thank you to the Higher Education

Statistics Agency for buying them all!

My fiancée, Anna, has had ME for seven years now and she speaks very highly of you and the work you do and I just wanted to say thank you for making her life a little easier, giving her and her mother support whenever they have needed it.

Sorry the money isn't much but hopefully this can make a difference and be used to help lots of other sufferers even if it's just for a moment.

The images in the card are various photographs, again taken by myself, of smoke from a candle, which was taken against a black background. Using computer software I was able to swap the colours to make a white background and some quite dark smoke. I then added colour to the image to make the smoke more striking. I have ended up with several fascinating images and shapes that are different every time.

I am now in the process of making some more and they are available through my website at [www.syco-still.net/cards/](http://www.syco-still.net/cards/) if anyone would like to make an order and all the profits made will continue to be sent to the Tymes Trust.

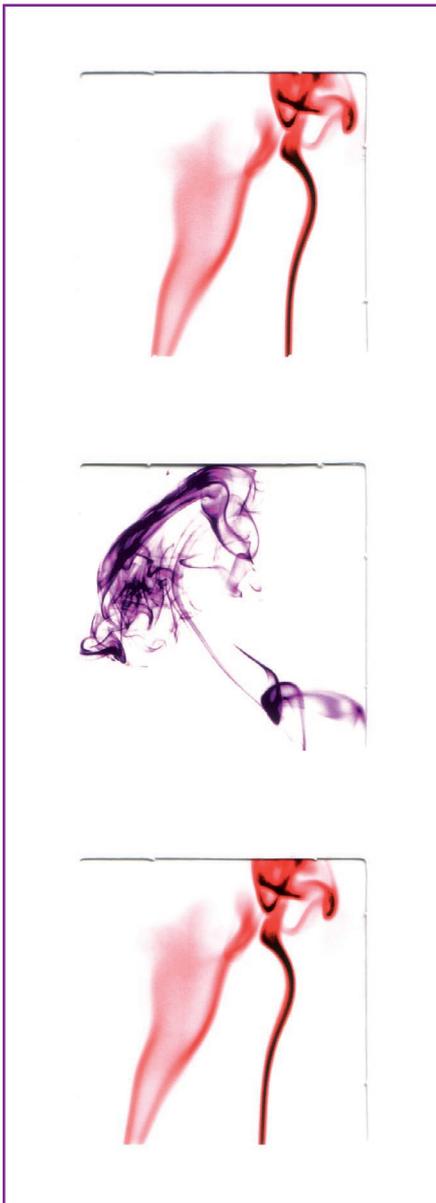
Thank you for all your support and kindness.

Mat Benfield

*Mat also has lots of pictures on his site. Check them out at [www.syco-still.net/blog/index.php?showimage=280](http://www.syco-still.net/blog/index.php?showimage=280)*



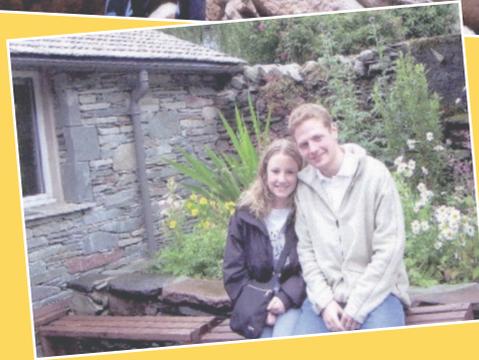
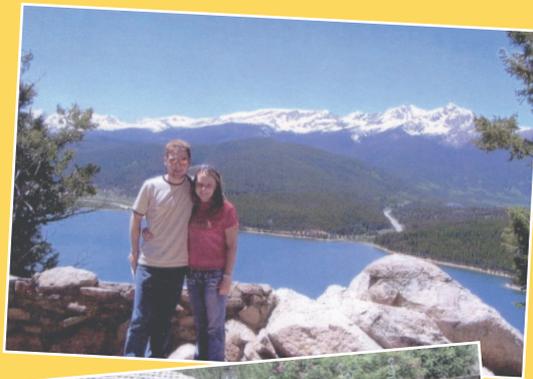
MAT BENFIELD'S SUPERB HANDMADE PHOTO-ART CARDS



Former member Chris Peachey sent us pictures with his fiancée. We wish them much happiness.

'All in all it's been a hectic but productive year and multi-tasking has been taken to the extreme!'

If you want to share your news with us, why not email us on the Contact Form at [www.tymestrust.org](http://www.tymestrust.org)?



We are glad to hear that Matthew Burke is back running. His mother Sue writes 'He is not sure if he will run Bristol Half Marathon this year but next time he runs he will do it in aid of ME.'

*Matthew and Sam Burke*



**Ladies Afternoon**  
 Sunday 4th February 2007  
 1pm - 5pm  
 at Kingswood Community Centre

**Demonstrations & mini-treatments**

**The BODY SHOP at Home**  
 Facials  
 Beauty On Your Door Step!  
 Indian Head Massage No Hands Massage  
 Nails

**WEIGHTWATCHERS**  
 Shopping at the mini-stores

**JEWELLERY**  
 by 1508  
 Knitwear & Ladieswear Sample Sale  
 Hand Made Cards  
 Crafts  
 Raffle  
 Tombola

Proceeds to support

**TYMES TRUST** Registered charity 1080905  
 The Young ME Sufferers Trust supports young people with ME / Chronic Fatigue Syndrome

**Friends of St Paul of the Cross Registered Charity 104989**  
 For SEN resources to support children with medical conditions

**Tickets £3 - Including tea, coffee, soft drink, biscuits (£1 for 11 to 16 year olds)**  
 Available from Reception at St Paul of the Cross 01242 224896  
 Friends Association Members or phone: The on 01242 70947

We are pleased to enclose a cheque for £360 from our fundraising event on 4th

Helen has had many ups and downs and missed a considerable amount of schooling. However, her school

not to be needed! She has sat and watched her friends enjoy themselves on many occasions, unable to join in herself, so taking part was a turning point for her. Although she was off school recovering after her return, Helen's confidence has grown.



We are hopeful that Helen will start at High School in September where we know she will be given the support she needs. We also know

we will continue to access your information and support!

February. The Ladies Afternoon was successful and raised a total of £720, the other £360 has been given to Helen's school, St Paul of the Cross, for SEN [Special Educational Needs] resources.

We were unaware of ME/CFS in young children prior to Helen's diagnosis at the age of 6, by which time she had been



does provide a very caring environment and we have maintained good relationships with staff despite our, at times, heated discussions! We feel that lack of support is a problem for the school - from the Local Education Authority etc. In Helen's case the school could not access any extra support as she did not meet the LEA's criteria for a Statement!

we will continue to access your information and support!

Regards  
 Tina Rogers-Smith



We don't know what the

future holds but she is much better and achieved a great deal on her school trip. Helens's dad went on the trip and was pleased

It is wonderful to have received so many letters for this issue from members who are able to do much more than before, but everyone's illness takes a different course and as always the most important thing is to stay within your personal limits. As Dr Darrel Ho-Yen says 'If you learn to live within the barriers, then the barriers expand.'

It is wonderful to have received so many letters for this issue from members who are able to do much more than before, but everyone's illness takes a different course and as always the most important thing is to stay within your personal limits. As Dr Darrel Ho-Yen says 'If you learn to live within the barriers, then the barriers expand.'

# Meet The Team

## Vera and Tom Kindlon

Irish ME Group, Dublin  
A Tymes Trust Partner Group

You might be interested to know that we sent Dr Alan Franklin's *The Doctor's Guide to ME in Children and Young People* ([www.tymestrust.org/pdfs/drguide.pdf](http://www.tymestrust.org/pdfs/drguide.pdf)) to over 2500 GPs in the Republic of Ireland. This is basically all of our GPs.

We got them printed as an 8-page booklet in black and white on Cream 80gsm A3 paper, folded and saddle stitched to A4 size.

We posted this along with the Canadian Overview and other information.

*Tom has evaluated The Royal College of Psychiatrists' publication 'Mental Health and Growing Up, Second Edition - Chronic fatigue syndrome: helping your child to get better' in light of the current 'evidence-based medicine' culture.*

I gave it low marks because of various statements for which I think there is little evidence.

For example it says 'Young people with CFS may quickly become very unfit from staying in bed, or just doing not very much for a long time. This causes rapid muscle loss

even in healthy people. All these complications make recovery more difficult.'

Where is the evidence for this? [In *The Doctor's Guide* Dr Alan Franklin said 'It is startling how little wasting is seen in young people with ME who also have an intact Central Nervous System even after prolonged bed rest and how quickly this is restored when they recover; **clinical experience shows that recovery is slow but spontaneous and does not require exercise programmes.**']



If there is no underlying disease, it isn't hard to re-condition people who are unfit. It's not easy in ME because there is an ongoing disease in at least some patients, which means exercise has risks - patients can't simply exercise like healthy people.

In their study *Time course of exercise induced alterations in daily activity in chronic fatigue syndrome* Black and McCully concluded 'Daily activity assessed via an accelerometer worn at the hip was divided into sleep, active, and walking periods. Over the first 4-10 days of walking, the subjects with CFS were able to reach the prescribed activity goals each day. After this time, walking and total activity counts decreased. Sedentary control subjects were able to maintain their daily walking and total activity goals throughout the four weeks.

'Unlike our previous interpretation of the data, we feel this new analysis suggests that CFS patients may develop exercise intolerance as demonstrated by reduced total activity after 4-10 days. The inability to sustain target activity levels, associated with pronounced worsening of symptomatology, suggests the subjects with CFS had reached their activity limit.' (*Dynamic Medicine* 2005; 4: 10 [www.dynamic-med.com/content/4/1/10](http://www.dynamic-med.com/content/4/1/10))

The Royal College says 'Often it is hard to know when to encourage your child, when to comfort them or when to put pressure on them.'

Should parents be putting pressure on their ill kids? Where is the evidence that parents should 'put pressure' on their kids?

## Dr Derryan Paul

### Mid and West Wales ME Group

A Tymes Trust Partner Group

I have much pleasure in enclosing a cheque for £25 for Tymes Trust, as a donation from our group. This is part of the proceeds from our supermarket collections in Aberystwyth last year. It comes with our warmest thanks to you for all that you are doing on behalf of young people with ME.

### Shopping?

IN ASSOCIATION WITH  
**amazon.co.uk**

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 make a helpful contribution to the Trust's work.



## Shannen Dabson Tymes Trust Young Advocate

I've recently had a bad spell and have had to go back to a wheelchair for the first time in over a year. I used to feel alright using it because it meant I could get out when I hadn't been able to for so long. This time I'd gotten used to going out - even on my own. I thought I'd never look back. So getting back into the chair this time was hard. I'm now 12 and felt that people would stare. I got very upset

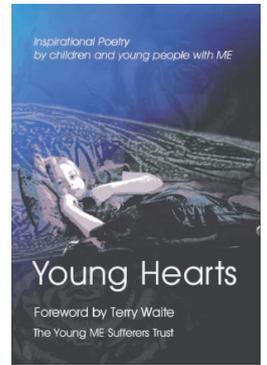
even though I knew it made sense. Some people do stare but I have to ignore them and some ask me what is wrong. I'm tempted to say that I've broken my leg as some days I can't face having to explain it all but at least I don't have to say I've fallen over ice skating and bruised my bottom.

Don't worry if you have to have a chair. Make it your own and let it show your personality. I have a nice blanket with Labradors. I sometimes have my dog or McFly/Blue Peter badges to give me courage.

*When we sent Shannen's school a copy of Young Hearts as part of our Advocacy Project, they invited her to make a presentation*

*at assembly. Shannen prepared a speech and was going to read 'My ME' by Rachael Marshall. Sadly illness prevented her going.*

*We explained that the assembly did not have to be on Young Hearts Day. Maybe your school could hold an ME assembly?*



## Insight

Reverend Philip Joy

Creativity has always been important to me, but especially so since I've been ill. I wrote the Harp Trio at a time when my health was going downhill fast. I found that it made me less depressed about my life because, even though I was in bed all day, I was creating something positive. I had to be careful though, as it was also very tiring!

For me the Trio was the beginning of a new direction. I was surrounded by sadness and frustrated by increasing disability, loss and isolation. But I trusted that beyond all that there was a God who was Good.

So I tried to write music that brought beauty into the world. I was pretty sure that the sadness would get included; it was the happiness I wanted to express!

So if you listen to my piece you'll hear a variety of emotions. Struggle, confusion, pain, anger - but also beauty, simplicity, joy and vitality.

The music does not tell a story as such; it is not 'programme music'. But you can be sure that whatever emotion you experience as you listen, whether positive or negative, is one an ME sufferer has experienced.

If you can find a creative outlet like music, art or poetry I am sure it will help you through the hard times. And if you can make it to the concert I hope my music will do for you what it did for me - lift you above the sadness into a whole new realm of hope.

*We would love to have people in the audience from many different groups on ME Awareness Day, health permitting of course, and if you are not otherwise committed.*

*We would be happy to read out the names of all groups represented at the event. If you can't come, a message of support would be very much appreciated. These can also be quoted.*

### REMEMBER THE CHILDREN *an evening of music and poetry*

**ME Awareness Day 2007**  
8pm Saturday 12th May 2007  
Brentwood Cathedral, Essex

#### Featuring

*broadcaster and poet*  
**STEWART HENDERSON**

#### ST BONAVENTURE'S BOYS' CHOIR

*soloists from the*  
**IPSWICH SUZUKI GROUP**

*soprano*  
**JACKIE PITTMAN**

*premiere of 'harp trio' by  
me sufferer and composer*  
**REVD PHILIP JOY**

*performed by*  
**THE TURNER ENSEMBLE**

*tickets £9.50 concessions £6.50  
advance bookings guarantee  
seats in the reserved area*

**BOX OFFICE 01277 841624**

*Remember the Children aims to  
increase awareness of ME in children  
and young people. In support of  
The Young ME Sufferers Trust*



# U 2 D o

# Things 4



We reckon Susie has excelled herself again with this beautiful Springtime drawing for you to colour. What do you think?

Bring it to life with your pens or pencils.

If you want to send us yours to see, get someone to make a photocopy for you to colour so you won't have to cut up your copy of Vision.

We'll give as many prizes as we can and we'll post it back if you send an A4 stamped addressed envelope.

Name  
Age  
Address  
Postcode

# COLOUR SUSIE'S SPRING!

## We're supporting

The Young ME Sufferers Trust  
www.tymestrust.org  
01245 401080

## SUPPORTING TT STICKERS!

You asked for them - so here they are! Tymes Trust stickers for all your letters, cards and other creative uses.

Choose Cheeky Teddies or Gentle Flowers

£1.25 per sheet including post and packing (2 sheets for £2). We think they'll be popular so try to let us know soon if you'd like some from the first batch.



## MARGERET'S SMALL CHANGE BOXES

When Trustee Sally Player suggested making collection boxes, Trustee Margaret Ross did!

On each box it says

*Your small change weighs you down.*

*ME weighs down the life of a child.*

*Lighten your load and help us lighten theirs.*



If you are making your own box don't forget to put the official charity number (1080985) on it.



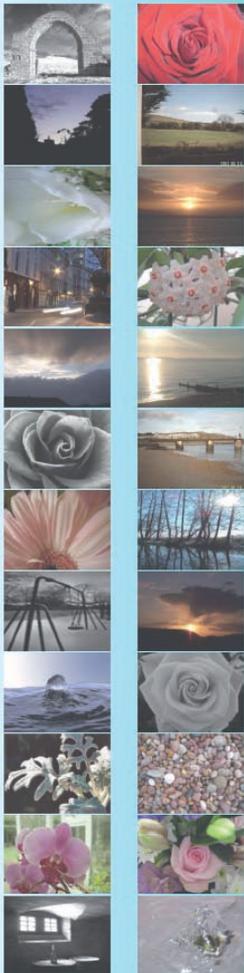
## FLUTTER BYS!

We've got some lovely new butterfly window clings - let us know if you would like a few.

## Energy Meltdown

### The Great Outdoors (and Indoors)

The sharp light of spring, the soft breeze of a summer's day, golden glows in autumn or crisp, crisp winter air - it's all here for all! You sofa, fans and bedroom buddies that are missing the great outdoors - bring it on in with these amazing photos.



Check out  
[www.energymeltdown.co.uk](http://www.energymeltdown.co.uk)

We did when we heard from Pippa Kearnes, who explained why she set up the site.

Pippa writes: 'I know a lot of people with ME who use their time to make things and a lot of them are extremely talented. Those that are perhaps not well enough to make things enjoy to look at things other people have made and on a gloomy day there are plenty of pictures to cheer people up.

I thought that a lot of people have access to the internet now so a website would be the best way to share and enjoy what we are able to do. Also it is a great way for healthy people to see what we are capable of even though we go through so much everyday.

## Friendship

*It's when you're sick and can't go ---*

*You learn what friendship's all about.*

*I try my best to keep in touch*

*But often can't do very ----.*

*A friend is one who'll be there still*

*No matter if I'm well or ---.*

*If I am feeling all alone*

*Good friends will visit, text or -----.*

*I'd rather have one real true -----*

*Than many more who just pretend.*

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

*It is the Trust's view that at some stage the medical establishment will need to separate 'ME' from 'CFS'. This can be done either by creating sub-groups within the Chronic Fatigue Syndrome label (less satisfactory) or by defining ME separately.*

The historical tangle created by inventing 'CFS', and incorporating ME into it, needs to be unravelled. We take the view that this is the most satisfactory approach for the sake of patients and medical accuracy.

Ours is a pioneering approach, but the Trust has never shrunk from that role. Our Executive Director, Jane Colby, was approached by Dr Byron Hyde from Canada, a major authority on ME, who was developing a new and testable ME Definition. Having worked with Dr Hyde on this, we have now published the new Nightingale Definition of ME at [www.tymestrust.org](http://www.tymestrust.org).

The National Institute for Clinical Excellence puts out guidelines on different medical conditions which doctors are expected to follow. In 2006, the Trust took part in a consultation process on NICE's proposed guideline for CFS/ME. We were unable to approve the final draft, which NICE intended to publish in April of this year, and we submitted a detailed analysis. We addressed both the helpful aspects of their draft, and the less helpful ones.

*The following text is taken from the Trust's Submission to NICE by Jane Colby*

**The Trust believes that the present draft of the NICE guideline on CFS/ME is unacceptable, and not fit for purpose for patients suffering from ME.**

### **Analysis of the Problem**

The problem NICE faces is that it has attempted to put together guidance on a medical condition that has been artificially constructed.

CFS is not a discrete disease, it is an arbitrary grouping of symptoms, now with the profile even further widened by NICE. By the very nature of the process by which 'CFS' was created, different pathologies must be trapped within its remit; descriptions of CFS always refer to it as a 'heterogeneous condition' eg the Report of the Chief Medical Officer's Working Group on CFS/ME published by the Dept of Health in 2002.

Those who coined the term CFS were divided as to the symptom profile they would research, rather than researching a specific and recognisable disease. Government, physicians and patients are all having to deal with the fall-out of this process.

In the Trust's opinion, this guideline as it stands would lead to an unprecedented degree of iatrogenic injury [damage caused by medical professionals] to people with genuine ME, particularly children, those in the early stages of ME, and the severely ill.

Those who are not yet severely ill risk being made so, both by the treatments recommended, and by the fact of relapses being trivialised by the term 'setbacks' and patients being urged to continue with programmes despite these setbacks. This is demonstrated in the many accounts we have been given over the years, together with numerous patient surveys such as that by the 25% Group. If a key symptom of a disease is post-exertional malaise, it is illogical and inappropriate to

prescribe exercise as a treatment and the damage done by such an approach is evident in patient histories.

Before CFS was born (originally for research purposes only) 'ME' was the name for a well-defined, virally triggered, potentially severe and chronic neurological disease. Incorporating it into a collection of symptoms in which 'chronic fatigue' is the main symptom masks its true nature.

The fact that the CFS construct has been taken into clinical use compounds the problem. This has put NICE in the position of issuing guidance on an unscientific basis, for a hopelessly mixed group of patients.

Consequently, if this guideline were published, physicians face the stark choice of ignoring NICE when dealing with patients who have ME rather than CFS, or risking actively causing harm to this group of patients. They would also have no guidance on how to distinguish this group.

Having seen and experienced what comes of trying to put together guidance for 'CFS/ME', the Trust now believes that ME and CFS should be the subject of separate guidelines. Despite the step forward that the (recently updated) Canadian Criteria for CFS/ME represented - criteria which the Trust was the first to recommend in the UK - we believe that ME should now be removed from the CFS bracket and steps taken to issue guidance to doctors as to its true nature, using information from appropriate ME specialists, who will not be those at present advising the government on CFS. They should be drawn from those who have the necessary knowledge, expertise and experience of examining and investigating ME patients and who

# Why CFS is not ME

## and the Trust's submission to NICE

can point to the infectious origin of ME, its known epidemiology, history of epidemics, known biomedical research profile, testable pathological changes, post mortem findings and other robust scientific evidence.

We respectfully submit as evidence selected quotes from the Nightingale Definition of ME by The Nightingale Research Foundation, Ottawa, Canada, with which our Executive Director Jane Colby was invited to assist. The Nightingale Definition will shortly be available in full.

The expertise and knowledge that NICE needs on ME is available. The Trust is dismayed that NICE has allowed such a narrow perspective to inform such vital work and requests that it reconsider the whole guideline in the light of our submission, our new evidence, and that of other patient organisations. [...]

What is new and different about the Nightingale ME Definition is the following:

**A Testable Definition:** The definition is set out in both a clinical diagnostic and scientifically testable fashion. This will allow the physician both an early diagnostic bedside or office understanding of the illness and a scientific and technological method to investigate and confirm the diagnosis. [...]

In the Nightingale Definition of ME, more than 30 physicians are listed who have to varying degrees also noted the historical and the more recent investigational findings. We recommend this definition to NICE.

### Helpful Statements

There are some helpful statements in the NICE guideline which we wish to recognise. One is that healthcare professionals for both adults and children should have the appropriate skills and expertise - but who is training them? If the training simply perpetuates the same inappropriate psychologically based attitudes to ME, then this worthy aim will produce harm rather than good.

The statement that paediatricians should follow advice from the Department for Education and Skills on education for sick children is helpful. However, the publication 'Access to Education for Children and Young People with Medical Needs' by the DfES contains ambiguities that have been the subject of personal discussion between Parliamentary Under-Secretary of State for Schools, Lord Adonis and the Young ME Sufferers Trust. Lord Adonis has, as a result, issued a clarification to state that a GP's support and advice

eg for tuition in the home, is valid. A sick child must legally be offered education by other means after 15 days of being unable to attend school through illness. Almost no family will see a paediatrician within this timescale. This should be reflected by NICE by referring to the usefulness of supportive advice from GPs as well as consultants in its guidance. Many GPs do not feel able to give such support at the moment or are ignored when they do.

Sharing supportive information with schools and making recommendations for adaptations to education are both worthy aims but this is only helpful when such information takes full account of the young person's needs, includes full recognition of the disabilities inherent in ME, and recognises that in the 21st century new forms of education are extremely useful to children with ME, such as interactive online education. The Trust works with Nisai Education to provide one such system, which is producing far better educational grades than conventional methods of education for children with ME. School is not a social club and it is perfectly possible to provide for social contact separately. The child has educational rights which are effectively contravened by physicians insisting on school attendance regardless of academic results. There is an increased tendency for medical studies to use attendance at school as a measure of recovery. School attendance is not a suitable measure of recovery in itself; studies should take account of whether or not the young person's academic achievement is on a par with that of their healthy peers as a result of going back into school.

The recommendation to liaise with Disability advisers is welcome.

The recommendation to consider the provision of equipment and aids such as wheelchairs, blue badges and stair lifts is particularly welcome as it is not only helpful in itself, it contradicts the view prevalent amongst many physicians that such provision will not facilitate recovery but will instead perpetuate disability.

### NICE Postpones Publication

After receiving this, and submissions from others, together with a joint statement by eight national ME organisations including the Trust - an unprecedented event - NICE withdrew its intention of publishing in April and postponed publication to August.



**A lot of the people who had actually investigated specific ME epidemics found the American definitions for Chronic Fatigue Syndrome quite aberrant. They really were not describing what we were seeing as ME patients. We were dealing with a post-infectious illness that was chronic, severe, and involved the central nervous system.**

**Why did you make a speciality of ME patients?**

It was pure accident. I had polio as a child and was laid up for about a year. I had a repeat encephalitis in 1984 and lost my ability to walk again and it took me a while to recover. So I was stuck in bed, having enormous difficulty getting around, even to the washroom, so I wrote a book. And then I had a friend come - an Irish physician. He said, 'It's too bad you're ill because we're having this great party in Montreux and I'm sure you would have liked to come!' And he went off to the party.

It was a party of about twenty people, mainly doctors, nurses and social workers. Somebody at the party had a viral infection and they all came down with this strange illness. Half of them got better almost immediately, within a matter of days, but about twelve of the twenty became so disabled that they were bedridden. When I heard about this, I didn't quite understand what was going on, and they certainly didn't understand what was going on.

Then my daughter came down with what I thought was a similar illness, a week or two after. She got well over a period of a month or so on her own, but as soon as she fell ill I phoned down to the Centre for Disease Control [CDC] in Atlanta and asked them if they had any idea what this was, and they said no, but there was someone at Harvard - Charles Poser, an expert in MS. They referred people to him because it had a lot of similarities with MS.

I phoned him and he put the name 'ME' on it. This was the early days when there were not many MRI scanners around - we're talking about 1984, 85. They were just starting, and CT scans missed a lot of cases of MS. So he was seeing all these early cases of ME, and saying, 'This is not MS, this is something entirely different, similar in many respects, but different.' He didn't know a great deal about it either and suggested I go and see some doctors in England, including James Mowbray, who had published on it. I was in no physical condition to do any travelling but I started reading all the material. This was in pre-computer times. All I had in bed with me was a word processor, so I bought an early Macintosh that I almost had to crank up!

There was no internet system then and it was very difficult to find anything about this, so I started phoning people. I gradually found an increasing number of people who knew other people who had investigated ME epidemics in the past. It became obvious to me that what we were dealing with was a post-infectious illness that was chronic, severe, and involved the central nervous system.

The other thing we felt was that it involved the musculo-skeletal system. We did a lot of work, but there was a general reaction against a central nervous system cause for this. The reaction didn't come from physicians, it came from patients. They were saying, 'This is not in my brain, there's nothing wrong with my brain, this is in my muscles; I can't move.'

A lot of these patients were being diagnosed as psychiatric, even at that time. So they were trying to avoid any connection with the central nervous system, thinking that what doctors were saying was that it was a psychiatric, hysterical type of illness.

Then we started looking back at similar patients we had seen prior to 1984. There were five or six who fitted. We weren't able to tell what was wrong with them. I wasn't running my practice then, I was trying to figure this out, thinking, 'I can look at it while I'm bedridden for the next six months and become knowledgeable about it.'

Well, years went by! Real information was hard to come by. Most of my sources - which may seem funny to you - turned out to be UK sources. The UK had the biggest movement against ME but it also had the people who were the most authoritative and the most knowledgeable. Most of these greats of the ME community no longer are with us, but in this period of 1985 to 1992/3 there were a lot of these people who'd known epidemics in the 1950s, and even from the 1930s.

### **Can you say more about the central nervous system changes?**

A large number of the patients that we had examined had definite central nervous system changes. The central nervous system changes in adults resembled in many ways the central nervous system changes in autistic children.

### **Did you say autistic children?**

Yes. The difference is that an autistic child falls ill usually in the first three or four years. When they lost say 40 or 50% of their central nervous cognitive abilities, they became autistic; when an adult lost 30 or 40% of their abilities, whether it was ability to make the muscles work or make their cardiovascular system or cognitive system work, most of them were still able to talk and walk to some degree, but what was different was that they could afford to lose where the child could not. I still believe that autistic children are really just a severe form of ME-type illness.

### **Viral damage, you mean?**

Auto-immune viral damage. It's probably like polio. Polio didn't cause the paralysis. What polio did was cause an inflammatory autoimmune injury of the small blood vessels going to the anterior horn cells. The

same thing is being found to be true in the last couple of years with MS patients. Again, you're looking at an autoimmune reaction at the small capillaries that are supplying energy, oxygen and whatever to the insulating cells around the neuron. [Professor Richard] Bruno's work has shown that polio didn't just affect the blood vessels to the anterior horn cells but also in the brain stem and in the subcortical areas of the brain.

### **So what about the Chronic Fatigue Syndrome label?**

I came to the conclusion, very soon into the 1990s, that we were dealing with two totally different spectrums of illness. I and a lot of the people who had actually investigated specific ME epidemics found the American definitions for Chronic Fatigue Syndrome quite aberrant. They really were not describing what we were seeing as ME patients.

And so, because we didn't have the funding, or the 'handshake' of the British or the American authorities, we were left out in the cold. I continued to work in this field nevertheless.

The whole concept of what ME is, is so clearly written down if you read the epidemic writings. It's only recently that I decided it's no use fighting the American-driven concept of Chronic Fatigue Syndrome any more. It's getting further and further away from what ME is, and was, and continues to be.

### **So there was a clear need to separate ME from CFS?**

This is what brought out the Nightingale ME Definition.

[www.tymestrust.org/pdfs/nightingaledefinition.pdf](http://www.tymestrust.org/pdfs/nightingaledefinition.pdf)

Dear Jane

Have been working around the clock seeing patients. I am happy that Betty Dowsett liked the Definition.

It is so different from any definition out there and as far as I am concerned, the only one based upon both history and the examination of thousands of ME and CFS patients. Thanks for your help.

Byron

**Leanne De Jager from South Africa** is our latest international member.

She has joined our 26+ group and would love to hear from anyone who wants a friend abroad. Send us a message and we'll forward it on for you.

**Dear TYMES,**

You were the first ME magazine I came across in 1996

and it was such a revelation to discover that others were experiencing the same horrible symptoms and experiences as myself. I remember in particular an article about using a wheelchair and how it gave me the courage to admit my need for one. Those two wheels gave me a freedom I hadn't had for quite some time and reduced my isolation over the next 7 years I had to use it for.

Over the years your magazine, or rather your fantastic members, have been a constant source of inspiration and admiration and I wanted to say thank you to them all. I have now made enough of an improvement to start university. Your advice and information has been invaluable so with much gratitude I say thank you for everything!

With love,  
Kelly Watson



**I took these photos of Rose** in my chair. What would be your reaction if you saw her coming towards you? I wish people would smile at me like that. What do I have to do?

Shannen Dabson



**I thought that I would just write a small note** and say how thankful I am for the issue of *Vision* that I found had arrived yesterday. It is so lovely to receive something that contains so much information about ME (even if I only have the stamina to read Seb's Manor at the back!) and fun competitions and things to colour.

I thought that also, I could write and tell people about the fun that can be had even if one is stuck in bed.

I have what can only be described as a 'busy' bedroom. Everywhere I look, there is something happening. Attached to my shelves are all manner of things, such as windchimes, bracelets, Japanese dolls and even a musical box. At my windows is a row of blue bottles, some

twigs and old moss collected from a woodland walk, a collection of Felixstowe beach pebbles and many potplants (each with names of course) and on every available surface unwittingly left without clutter for a second there are cushions, scarves, hats, bags, ornaments, plants, blankets and lately, a fruit basket.

I have been in bed now for almost two months. I am not however bored yet or wishing for a drastic room make-over. And those are the benefits of a busy room. Oh yes! And also a busy tidy room, I find, is a people magnet; so friends and family will be drawn in to keep you company. I am still working out whether this is a good thing or not. People or no people, we still need our sleep.

Felicity Anne Catherine Wood





**Married in a lovely country church** - something which not so long ago would have seemed someone else's dream. Feels as if this illness has been kicked into the corner and made to realise life goes on! 17 years to climb the mountain of ME but the view is breathtaking! Please pass this on to anyone feeling down or uncertain of getting through tough times.

Love to you all  
Toria Cox

*Toria was for some time one of our Advice Line Team.*

*We hope Toria's story will encourage those of you who haven't seen an improvement in your ME over long periods of time. Human beings have*

*wonderful self-healing properties, so long as we look after ourselves, don't overdo things, eat as well as possible (bearing in mind the sensitivities some people develop to certain foods) and give our bodies lots of love and care. Love is the most wonderful healing mechanism.*

*Everyone on our Advice Line really cares, as they give their time free of charge. They all have experience of ME as well as lots of reliable information. Do telephone if you need advice, and if you should get our answerphone message instead of a live person, do leave a message as we will always call you back.*



**Could you be a friendly voice on the telephone for two hours a week?**  
Call 01245 401080 or email us on the Contact Form at [www.tymestrust.org](http://www.tymestrust.org)

**Thank you so much** for all the booklets and information you sent to Steph and myself. It breaks my heart to read the letters and poems from the ME patients and their parents. Steph saw a councillor for a while, and then a specialist. I wish with all my heart that the children and adults who are suffering could enjoy the changes Steph is feeling. ME is always 'there' but being listened to, believed and liked for who and what she is has enabled Steph to become a beautiful, more confident young lady.

Chris and Steph Angus

**Whenever you write or email us, don't forget to say if you would like us to quote you in Vision. Send a photo too if you can!**

## THE Question

### Would you like us to recognise your best teacher?

In each issue of *Vision* we ask your views on a particular topic. As you know, whenever we seek our readers' views, we act on what you tell us.

Many of you say that your teachers still don't really understand ME. One of the most frequently used publications on our website is *The SENCO's Key Role in Supporting Pupils with CFS/ME* and you may find it helpful to give them a copy.

But what about the teachers who do know about ME, and who have gone out of their way to help and support you? Would you like us to recognise their efforts on your behalf?

Send us the full name of the teacher (check the spelling if you need to) and the address of the school, and we will send them our Letter of Commendation signed by Founder Patron Lord Clement-Jones.

If you also send a photo of you and your teacher together, we'll publish it in *Vision*.

Write to: *The Question*, PO Box 4347, Stock, Essex, CM4 9TE

# SEB'S MANOR



## Sebastian Says

I've been on holiday again! Yeehaa! I went to see Chloe - see me on page 23.

Can I come and stay with YOU now? I'm getting really used to journeys with Royal Mail. I'm thinking of travelling by Large Letter Post next time. It'd be great to have a comfy padded bag to relax in.

BTW, I don't know about you but I got very muddled when the new postal system came in. As you know, I'm in charge of the prizes. But NOW some of my parcels cost twice as much to send!

Some prizes can go Letter Post or Large Letter Post but as soon as they get thick and won't fit into the Post Office measuring slot, they get called a Packet - and cost one!

Once I got my legs tangled up in the slot. I was stuck till Lesley, the kind Postmistress at Stock village, got me out. I was wearing my new trainers at the time - I got the idea from a cool card I was sent, showing me with some on.



I'm not vain of course, but I DO like to get pictures of me. Can you find me any more? And when you write to me, make sure to put the right postage on, so it gets here safely.

I've got some more superb colourings to show you. Congratulations to Eleri Messenger who counted Susie's Hearts as well as colouring them. There were 37 hearts and she got a prize for it.

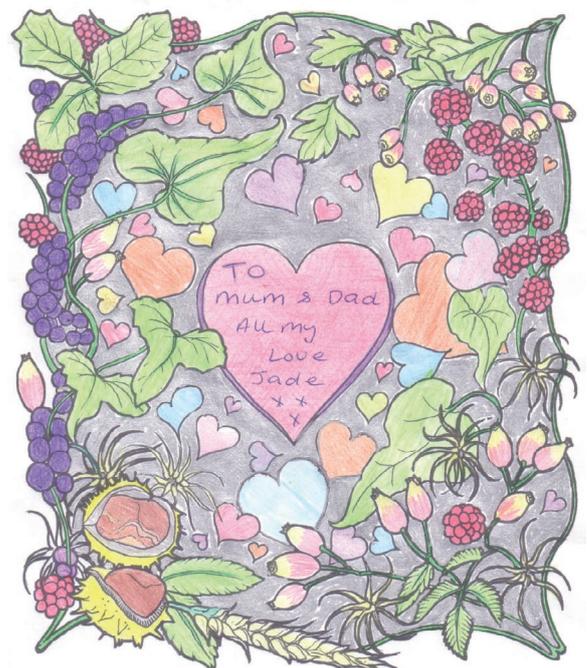
Thank you Tymes for everything you do :-). I photocopied and coloured in Suzie's Hearts as I didn't want to cut up my copy of Vision.

I have problems with my hands and arms and can't write properly or hold pens well so I coloured the picture in with extra thick pens but it worked out fairly well and I enjoyed trying it.

Sarah Coulbert, Age 20 (!!)



Sarah Coulbert



Jade Smith

# CHOOSE MY NEW BIRTHDAY!

I need another birthday. It has come to my attention that all the best people have two. How I can have gone on so long with only one I really don't know.

The question is when it should be. There are so many days to choose from - apparently over 300! And I can't have Christmas or New Year or something else distracting people from National Seb Day; that would never do.

Can you help me? Send me your suggestion of when my official birthday should be and why you chose that day.



After I got back from holiday with Chloe, she wrote to ask: 'Is there any way that I can draw pictures for your great magazine?'

YES PLEASE! To start with I've grabbed some you sent with your letter for my very first Seb's Art Spot.

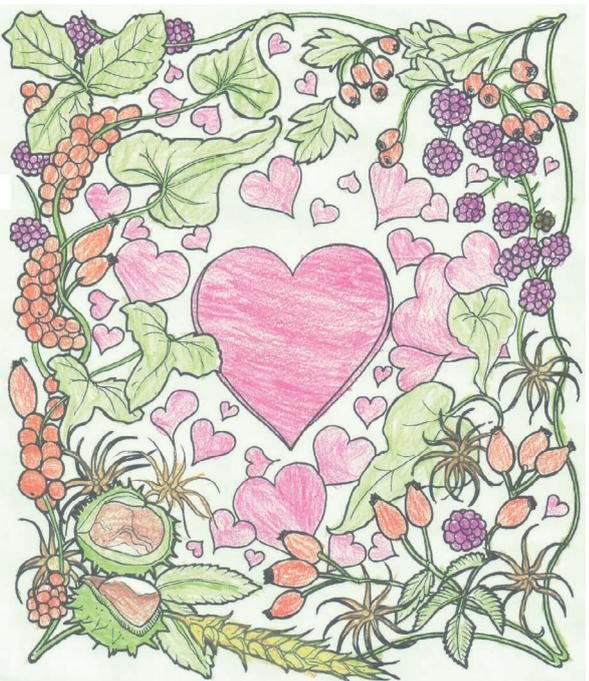
It would be cool to have another Art Spot next time. Who will send me pictures for that then?



Eleri Messenger



Bruce Jayasinghe



The secret's out! I've been keeping an album of my holiday photos. (And other Important Events of course - I'm going to the House of Lords to hear the speeches!) Here are some photos from my holiday with Cheryl Nekt. Ah, happy days!



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



# A letter from ...

Dear All,

I've had ME since I was a small child. I've enjoyed reading Tymes Trust's magazines for some time now. I've enclosed a brief article about my experiences with university and ME in the hope that people might find it encouraging. Thank you to everyone at Tymes Trust for all the wonderful work you do.

Best wishes  
Bess Rhodes

*Starting at university is exhausting for any fresher. New students rush from lecture theatres to libraries; they trail round fairs where everything from film clubs to Frisbee try to enlist them; they go in gaggles to parties. Adding to this social whirl is the desperate wish to make a success of it, to do well academically, to make good friends, to cope with living as an adult away from your parents. If you have ME there is an extra fear - will your health be up to it?*

*For most ME sufferers simply getting into a university is an achievement.*

*I developed ME when I was seven, and as a result was home educated for the first two years of junior school. By the time I was nine I was well enough for school, I caught up academically and it seemed as though I was largely recovered. Unfortunately the shift to secondary school, and the longer days and larger workload meant that I had a serious relapse part way through year seven. Anxious to keep up with work, I would beg my parents to take me to school. Yet when I got there I would be so unwell that my teachers would ask my mother to come and collect me [...]*

*I am now in my third year at university. Things haven't been perfect. I've had the occasional relapse when I've tried to do too much (notably when I attempted to juggle several societies plus academic work). I have to be more organised than many of my fellow students, as for me, the all-night essay crisis simply isn't an option!*

If you aren't well enough to attend a university, we suggest you consider studying with the Open University. In our experience they have been very helpful to students with ME.



Dear All,

I am sorry that I have not been able to write to you sooner, but I have not been well on and off for a while. I am though gradually improving. Anyway I would like to thank you all very much for the little fluffy dog you sent me. He is very cute and keeps me company on my bad days. I have called him Patch and I think it suits him very well. Here is a photo of me holding him - I hope you like it. Once again thank you all very much.

Katy Lagden (aged 12)



My daughter Lucy went to hospital on 18th May 2006 in a state of near-collapse, having dropped out of school because of ME in April 2005. She was awarded her GCSE grades under Special Circumstances. She is much better and will be leaving hospital as soon as a community placement is found and I gather social services are at last near to finding one. She is now fully mobile, self-caring, eating well and up and about most of the time, walking half an hour

a day, needing 4 rests a day and is on a multidisciplinary approach.

She looks forward to her Listening Books.

Kind regards  
Rosemary Rowett

*The Trust has arranged for our members to have free membership of the Listening Library. Lucy has applied to join. Let us know if you would like to apply too and we'll send you the form.*



**Day 1** This cool place is right next door to Chloe's house. I had a great time spinning my webs all over it. The owner wasn't too cross!

**Day 2** Archery makes me dizzy!



**Day 6**  
Cool  
Pagoda at  
Carlisle  
Park



Chloe, Amber and Seb with Sugar



## Super Spider At Large Again

When Seb arrived at our house, Amber (my sister) and I squealed with joy and gave him a huge cuddle!

Prowler, his racing pal from last time he came, was very happy. The five star hotel (a doll's house) that he stayed in last time was all booked up and the price rates had gone up, so we hired a Playmobil holiday house, with views over a golf course and the sea. Seb enjoyed the barbeque that the Playmobil lent to us.

## ACROSTIC

*An acrostic is a poem where the first letter of every line spells a word.*

*November is in autumn when the leaves fall off the trees,  
Over the hills they wander, travelling in the breeze,  
Very cold and chilly when frost is on the ground,  
Everywhere is greyness and no children in the playground,  
Mum is wrapping everyone in hats and gloves and scarves,  
"Be careful where you're walking, you might slip on the paths,"  
Everything is greyness and grey clouds fill the sky,  
Remember that it's Christmas once November has passed by.*

*Zoe Hutber*

*Zoe not only won the Virtual Tour calendar for the first correct answer in our missing words poem, she also won a prize for her acrostic.*



**Day 3** We went for a wheelchair ride at Talkin Tarn. The birds thought I was a snack!



**Day 4** Had some work to catch up on. Boo Hiss!



**Day 5**  
Fun at  
the Park

The cats greeted him; they obviously recognised him. This time he wasn't almost recycled as he stuck close to me all the time.

On his last day he was treated to a movie in the lounge - Stormbreaker!

Soon after Seb arrived, the Chamonix bear arrived (Sugar). They went to the park and had a great time.

Seb really enjoyed his stay and one day maybe he'll come again.

Love Chloe xxx



# Shirley Conran Writing Competition

## What makes you happy?

Shirley would like your answers on a postcard - plain postcards, picture postcards, or if you don't have one (we know that many of you can't go out) you could cut up a used greetings card and write on the back of the picture. Ask someone nicely to post it if you're not well enough. You all have something valuable to say - and we are waiting to hear! Shirley, a patron of the Trust, has donated £100 for your prizes, so off you go!

## Young Hearts



BBC presenter Stewart Henderson will be reading from Young Hearts, our moving book of poetry by children and young people with ME, at Brentwood Cathedral, Essex on Saturday 12 May (ME Awareness Day 2007). We should love to see your family there (details on page 11).



The Warwick Castle launch by Terry Waite, former Special Envoy to the Archbishop of Canterbury, is still fresh in our minds as we move into the next phase of Young Hearts advocacy. Our grant from Essex Community Foundation Local Network Fund has already provided all Essex GP



surgeries, secondary schools and main libraries with a copy of Young Hearts. A television interview is at [www.tymestrust.org](http://www.tymestrust.org), along with a Special Children review.

Terry Waite says in his introduction to Young Hearts: 'Suffering need not destroy.' Or as one young writer put it:

"My world's stopped, but life goes on  
And I've time to drink in each new dawn."

## Answers On A Postcard

Talking of postcards, we thought you might like to see our Welcome Postcard that new members get with their Welcome Pack.

And here's our new Sympathy Teddy - a little fridge magnet showing our Tymes Trust Ted, who's rather the worse for wear (as you can see) and therefore can sympathise with your difficulties. In fact, however you're feeling, he can relate to that!

Can you choose a name for him? Winners will receive a Ted of their own to keep on the fridge or the microwave, with our details to make it easy to get in touch.



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[www.tymestrust.org](http://www.tymestrust.org)

01245 401080

'Quite. I can relate to that.'



### WELCOME

To welcome you to the Trust. We are so sorry that your family has been affected by illness but we hope you will not feel so alone now. Find your Sympathy Teddy enclosed; magnetic to keep our details handy on microwave or fridge.

**TYMES TRUST**

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