

The Young ME Sufferers Trust
Autumn 2005
£2-95

Vision

**CAMPAIGNING
IN THE HOUSE
OF LORDS**

The Countess of Mar

**MEET OUR NEW
PATRONS**

Terry Waite CBE

EXERCISE AND ME

New Research

THE BRIEF

Centre pullout:

Launching our Guidelines
for Educational
Psychologists



NEW REPORT: OUR NEEDS OUR LIVES

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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

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 Patrons Earl Howe Barbara Windsor
 Shirley Conran Terry Waite
 The Countess of Mar

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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

A vital part of our *Vision* project is to campaign and lobby for the interests of young people with ME. As I write, new Government funded 'CFS/ME' clinics have been opening up around the country. But what do you really want from such clinics?

With our grant from the Local Network Fund for Children and Young People we have investigated what young people with ME in Essex, and their families, require from their new local service. For comparison, we also took soundings from families around the country, and from our Focus Group. From the answers we received, the views of young people with ME in different areas are similar. You can find some of them on page 5.

These views are now published in the Trust's latest report *Our Needs Our Lives*, available on our website at www.tymestrust.org along with all our other reports, self-help leaflets and our professional guides, which can help your doctors and teachers to support you. Online publications can benefit people right around the world. An email from the USA reads:

'I was a high school teacher before coming down with CFS in 1994. I also have a 14 year old daughter who has had it for 4 years. Even though we are basically housebound we are still quite happy, close knit and refuse to let CFS get us down. Thanks so much for your web site. Hopefully some day I'll be able to give back and help others the way you have so beautifully done.'

LS, America



Essex Community Foundation invited us to give a presentation on the work of the Trust. Member Jack Granby and his mother Jane took part. Jo Murphy, Marketing Officer at the Foundation wrote to us:

'Thank you so much for joining us at Ingatestone Hall last night and for agreeing to speak about the work of Tymes Trust. The audience were really interested to hear about the work that you are doing to support young people with ME and were very impressed with the presentation by Jack and his mum which really put

into perspective the challenges that young people with ME and their families have to face. I do hope you enjoyed the evening as much as we did and thank you once again.

Jo Murphy

Following this presentation, George Malinowsky, Commissioning Manager for Southend Primary Care Trust and Dr Nigel Hunt, GP and Associate Director of Post Graduate GP Education, Eastern Deanery, attended the formal launch of *Our Needs Our Lives* at Rivermeadgate Surgery, Chelmsford.

The PCT are now using the report to inform their services and we hope that it will also be helpful to those of you living in other areas, who can use the report to demonstrate what young people think and need, and to lobby for their own local services. The project was funded by the Local Network Fund for Children and Young People. We have now received a further grant for our work in Essex.

This issue of VISION is rich with your poetry, messages and experience and, as usual, carries information for the whole family and interested professionals. Let us know your views.

Once again, I thank Keith and Sally Player for holding our summer Open Day at Westlands Nursery and Garden, Rettendon. A wonderful day, as always.



Sally in her garden

Keith Harley
Chair of Trustees



Meet Our Patrons

I'm delighted to welcome Terry Waite CBE as a new patron of Tymes Trust.

Terry's hallmark is courage and determination in adversity, a wonderful inspiration for us all.

Lord Clement-Jones CBE
Founder Patron



On 14 July a debate was held in the House of Lords in which Lord Clement-Jones stated: 'Finally, I want to address the educational needs of children with ME, which [...] certainly requires special attention. The charity with which I am involved, Tymes Trust, runs an advice line and does a number of other activities involving children with ME. It is the biggest cause of long-term sickness absence from school. Many children with ME are still not being offered educationally suitable provision for their needs, and they are not enabled to perform to their ability in exams.'

Education Minister Lord Adonis: 'A civilised society is judged by the way in which it treats its most vulnerable members and the equal worth that it accords them with their peers. [...] Our duty to them is not merely one of care but to enable them to reach their full potential and to give them and their parents the educational choices required to achieve that potential. That is the aim of government policy.'

Hansard 14 July 2005



Newsflash

As we go to print, Barbara Windsor MBE is returning to her part as Peggy Mitchell in *Eastenders*.

Barbara says, 'I am really looking forward to it and I shall be thinking of you all. I hope you have had a lovely summer - do take care of yourselves.'

Terry Waite CBE

In *Tymes Magazine* Issue 44 Summer 2003, Terry said of the name Chronic Fatigue Syndrome: 'I would say that it conveys to the public an inaccurate and incomplete image.'



Since then he has kindly written a foreword for *Young Hearts* and launched the book at Warwick Castle.

Read the complete interview at www.tymestrust.org or send for a back copy of the magazine at the special price of £1.50 including postage.

Shirley Conran OBE

An invitation from Shirley Conran OBE

Shirley invites you to join in another writing competition. 'Answers on a postcard please!' Her theme is: 'What I would like to do this autumn.'



If you find it easier to type than to write, send an email. It must still be short; *something that would fit on a postcard.*

In the last Shirley Conran writing competition, the entries were so good and so varied (all different ages) that all entries deserved – and received – a prize.

Send emails from the Contact Us page at www.tymestrust.org



The Countess of Mar

For an interview with The Countess of Mar, see pages 16-18



In The Spotlight: Our Needs Our Lives

What Young People with ME Require from a CFS/ME Clinic

It has been very disturbing and distressing for us to read, over a period of years, the many sad letters and emails we receive from children and young people with ME and their families whose needs are not being met.

The great majority report feeling disempowered and ignored. They report decisions that will profoundly affect their lives being taken out of their hands, with little understanding or consultation. They report ending up even more ill, with no suitable education or medical support. [...] All too often, families and children contacting the Advice Line report not being given choices about how they are cared for, or about the treatment they are offered. [...]

When we announced that we would be studying what young people and their parents actually need from the 'CFS/ME' services being developed with Government money, our study was widely welcomed. [...] We can see that what families want and need is consistent from area to area, and that in producing this report focusing on the charity's home county of Essex the Trust has also potentially helped children in the rest of the country, who will be able to use the report to explain what services they need in their areas also.

Taken from Our Needs Our Lives

Essex families answered a range of questions developed with Dr Nigel Hunt, GP and Associate Director of Post Graduate GP Education, Eastern Deanery; views from our Focus Group and over a hundred members from other areas were included for comparison.

This selection of views expressed shows that people want practical support:

- 96% would like a choice of which professional co-ordinates their care

- 96% said the clinic should help with getting a diagnosis
- 92% wanted the clinic to provide a helpline
- 88% said the clinic team should hold surgeries in different areas
- 88% said the clinic should help with getting physical aids eg wheelchairs, stairlifts
- 88% thought the clinic should assist with obtaining suitable education under the law eg home tuition, virtual education, part-time attendance, modified curriculum, special arrangements for exams
- 79% wanted the clinic to provide support for carers
- 0% chose morning as the best time for appointments with 79% finding midday or afternoon best

'The new clinic should support the Tymes Trustcard.' Focus Group

Psychiatrists and psychologists

92% did not think psychologists or psychiatrists should automatically be involved in the care of children and young people with ME. Asked to list circumstances in which they felt a psychiatrist could be helpful, people suggested: depression; coping with the illness if the young person so wished; if another psychiatric illness developed; if it has all become too much and the young person had expressed thoughts of self-harming.

Our Needs Our Lives is on the publications page at www.tymestrust.org

Presentation copies are available for £7.00 including postage and packing

Project funded by the Local Network Fund for children and young people

Dear Jennie

The *ME and My Friends* leaflets have been very useful. Since I sent them to my closest friends they have been in contact much more and are much more understanding about my ME/CFS.

I would also like to thank the Trust on behalf of both my brother and myself, since he is very happy with the gift you sent him. He has drawn pictures for me and my family with the pens. They were a perfect gift as he is very creative! He is really pleased with them and I would like to thank you because it enabled me to show him how lucky I am to have him as my brother.

I am not feeling too great at the moment but it cheers me up to hear from you as it reminds me there are other people who feel the same as I do.

Best wishes,
Sara

You can also find ME and My Friends at www.tymestrust.org



Would you like us to send some pens to a friend or relative who has been kind to you? Let us know their name and address.

I must congratulate you on the commentary on the Canadian Guidelines in the *Tymes Trust View* at www.tymestrust.org I have also now read the Australian Guidelines and agree absolutely with your comments. Congratulations on this excellent work by TT.

Jacqui Footman
Publicity Officer,
South Molton M.E. Support Group

What you think

Free Over 16 Virtual Education

I wanted to write and thank you from the bottom of my heart for organising your partnership with Nisai Education which I am delighted to tell you has now worked to our benefit.

As you know I have been speaking to them for quite some while about Elizabeth doing two A levels. I phoned to organise her registration form. As usual, Preya Dattani was very helpful and told me that as Elizabeth was 16 and because she is a member of Tymes Trust she should be eligible for funding from the Learning and Skills Council. I sent off her application form and this afternoon received a call from Preya confirming that the funding is in place.

I find it impossible to believe that we have managed to get funding without having to fill in endless forms and without having to face endless bureaucracy.

We are over the moon about this. For most of the time I have hit my head against a very hard brick wall, trying to persuade school, friends and even family that she really is not well at all. It is so good to know that she is eligible for this funding. It has given her a real boost.

It is refreshing that someone is ahead of the game and wanting to help, rather than having to beg for a few crumbs off the plate. I should tell you that Preya told me that every parent who she talks to from Tymes Trust is full of admiration for your charity and your hard work.

Once again, a very big thank you from me and from Elizabeth who has got a very big smile on her face. We are still all floating on air. Her friends were very impressed that she has got this funding!

Jane Colley

A few places are still left on this scheme. See the Brief for more details

Jane has now joined our Advice Line Team. If you would like to join, please contact us. Two hours per week would be the maximum commitment.

I would like to continue receiving VISION so I have enclosed my 26+ subscription. I enjoy it because it is so positive. I feel that an optimistic approach to an illness or disability is really important, when sometimes all you are left with is hope.

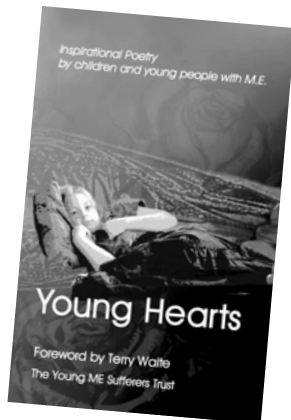
I am sorry that I haven't written to thank you sooner for answering my query in the March/April issue of VISION and in such a comprehensive way, I didn't expect that at all! I will have to write with my thoughts in general more often!

Kirsty Hinton

Kirsty asked us to explain our biomedical research with MERGE. We interviewed Dr Vance Spence (see VISION March/April 2005)



A little while ago we sent a copy of *Young Hearts* to my daughter's consultant, who wrote us a lovely letter: 'Thank you so much for sending me the anthology of rhymes written by children and young people with ME. I shall enjoy reading expressions of real feelings by the sufferers of ME, and this would no doubt have a positive impact on my professional practice.'



We happened to be seeing him the following day and he was very impressed.

Jane Colley

You can watch an ITV Central feature about Young Hearts with Jade Scarrott's mum and Jane Colby at www.tymestrust.org

Thank you so much for the copy of *Our Needs Our Lives*. My daughter and I have both read it and I am telling people about it. It is a great document and, as always, very positive, so I hope that staff in the new clinics will read it and use it. Well done for all your hard work and determination.

It is shocking to read that 25% of families in your survey had had a professional suggesting the illness was caused by the parents. This is the visible tip of the iceberg of disbelief and we so want the situation to improve. I hope that *Our Needs Our Lives* will go to the right people to make this happen. I'm taking it to our workshop on Disbelief and Its Effects.

Pat Williams

I found the Report very interesting to read and it also contained interesting comments from sufferers. It lets other people know just what sufferers need or require.

Vivienne Mills

Secretary/Newsletter Editor, Colchester ME Self Help Group. Vivienne and her daughter both have ME.

*You can also read *Our Needs Our Lives* at www.tymestrust.org*



Dear Jane

I would love to speak to you at your Norwich talk, but realise that everyone else will want a little bit of you as well. Keep up all your good work. We really have appreciated TYMES although we've been silent recipients. This is the first time in 11 years that I've even been able to consider giving anything back to the people who have been there for us, Laura has been so ill for so long. Hope your own health is holding up.

Love and best wishes

Lesley Judd

(I am Laura's mum, nurse, confidant, chief cook and bottle washer etc!)

To get a DVD of Jane's talk, telephone our Partner Group ME Support Norfolk on 01603 745101.

What have you been doing?

FUDGE GOES TO PARIS

It's hard to find something to do that's enjoyable but not exhausting. We suggest that you take photos. We rummaged in our photo box and found Fudge's holiday snaps. Remember when Fudge went on holiday with Cheryl Neyt? They went to Disneyland as Cheryl had got strong enough to make the trip.



The team is ready to start their journey.



We got there in no time on the Eurostar.



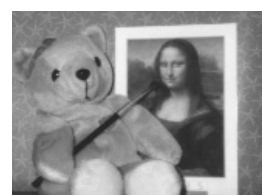
Arrived safely... that case was heavy!



Here I am outside the the Sacre Coeur



This Louvre place was very interesting! But very big with so many things in it. The famous Mona Lisa picture is kept here.



My inspirational attempt at painting!



A great view and welcome rest.

Congratulations to Cheryl for these great photos. Not all of you are well enough to go away for holidays so why not make your own photo storyboard of your garden or home for us to publish?



Fudge says: 'I just heard - another cheque arrived from Amazon! Thank you to everyone who is remembering to go to www.tymestrust.org first, when they buy things from Amazon. Once you are there, click on the Amazon link and they will make a donation to the Trust. Fab!'

Shannen Dabson says: 'Don't be scared'

I have just come out of hospital. If something like this happens to anyone else the ambulance is nothing to be scared of. It was wonderful – really exciting. But I did become homesick. The best bit was when visitors came to see me.

It did get boring just lying there all week but they sent round a clown doctor to entertain us. The bed was good too – it did whatever you wanted. I couldn't believe how early they get you up – I needed a rest when I got home.

Although there was lots to do in hospital there is very little to look at unless you can wander around. If I ever went to hospital again I would take lots of home comforts with me. I'd take photos to look at.

When I got home my aunt had decorated the place with Welcome Home signs and balloons. There's no place like home.

The night before I came home I wished for a fairy to make me well. I'm now much better. I do believe in fairies, I do, I do.

Shannen Dabson



In a clearing in a silent wood
Where silver moonbeams shine down
Hundreds of tiny sparkling fairies
Dance upon the ground
Trees whisper their secrets to each other
As all flowers dance and sway
In time to the sweet fairy music
And the animals run and play

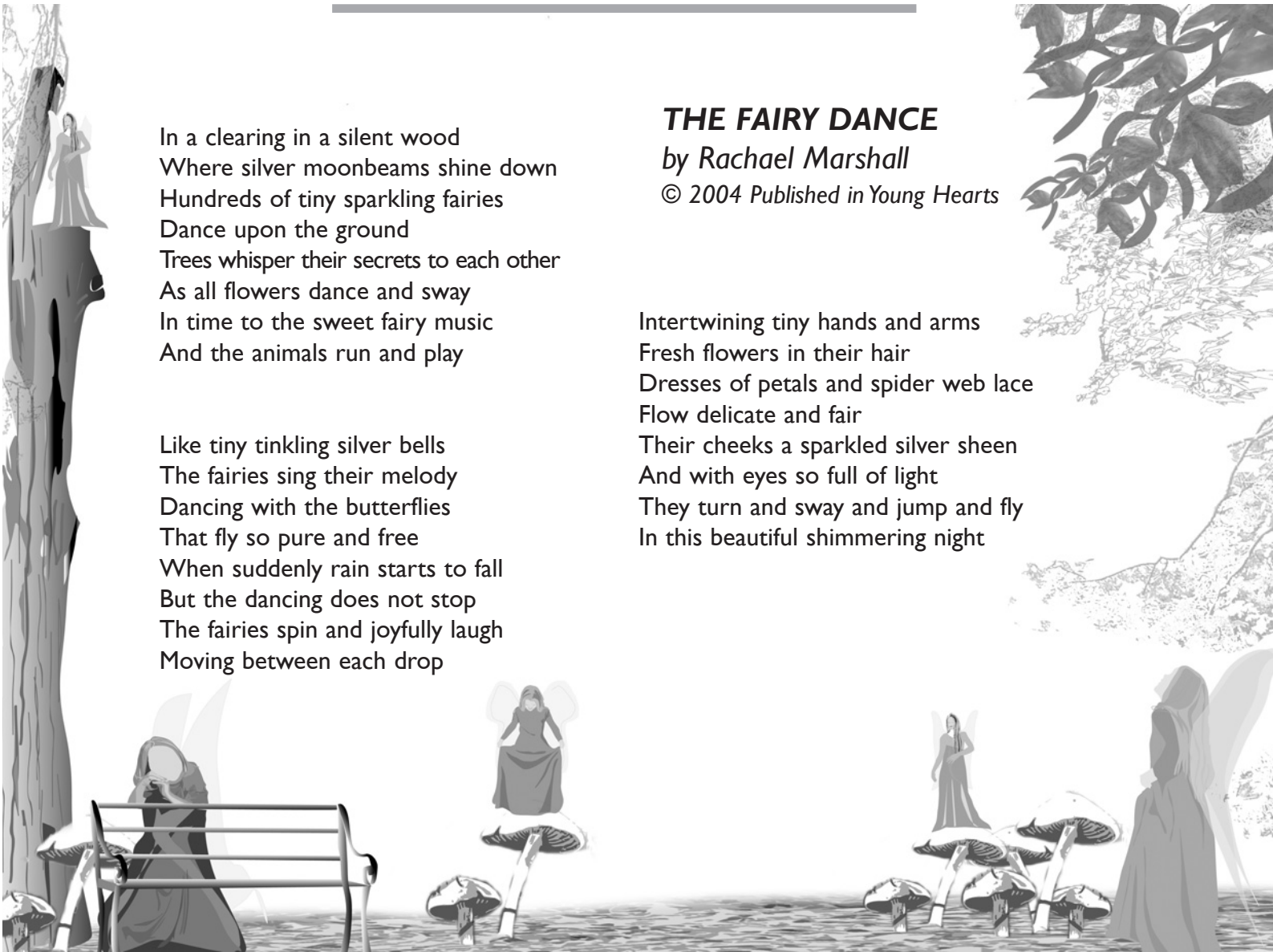
Like tiny tinkling silver bells
The fairies sing their melody
Dancing with the butterflies
That fly so pure and free
When suddenly rain starts to fall
But the dancing does not stop
The fairies spin and joyfully laugh
Moving between each drop

THE FAIRY DANCE

by Rachael Marshall

© 2004 Published in *Young Hearts*

Intertwining tiny hands and arms
Fresh flowers in their hair
Dresses of petals and spider web lace
Flow delicate and fair
Their cheeks a sparkled silver sheen
And with eyes so full of light
They turn and sway and jump and fly
In this beautiful shimmering night



We are proud of all the poetry that Young Hearts has inspired. Keep writing.

Meet The Team

Marathon

They run a marathon, not of miles, but of years,
But they keep pressing on, through the pain and the tears,
Drained by the sweat, struggling to breathe,
Fighting through their fears, and the past they must leave.

They run a marathon not chosen or desired,
No option to drop out when their hearts are growing tired.
Their feet are wearing blisters, their skin is turning cold ,
Not knowing how much longer their struggle will unfold.

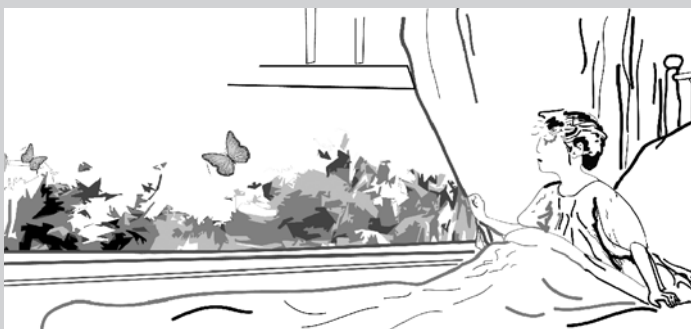
They run a marathon, but not past crowds of cheers,
Forgotten and rejected, sometimes even jeered,
But they are not alone, together they find strength,
For they find a special friendship that will go to any length.

They run a marathon. They are brave, they are bold,
So much they have learnt to share with the world.
Through the loss and the strain they stagger just to live,
But they keep pushing on for all they have to give.

They run a marathon, not for money or for fame,
But the dream that they carry still burns through the rain,
Defying despair against all the odds,
They keep fighting on whatever it may cost.

They run a marathon, the greatest of them all,
For if they give up now it's their lives that will fall,
So for the future glory, for the hearts that it will mend,
They run a marathon, keep fighting to the end.

Robin Sansom



© 2004 Young Hearts



**FATIMA
CELESTINO -
OUR VERY
OWN RUNNER!**

Hello Everyone

I am almost a fitness freak and as such I do a lot of running and cycling. A while back on considering to run the London Marathon I was introduced to the idea of running for a charity rather than run purely for my own personal gain and enjoyment.

Since then I have been looking for a charity I felt was a worthwhile cause – unfortunately, they all are! I ended up deciding on a charity that dealt with children – yours.

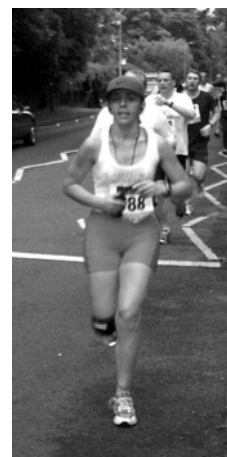
First I wrote to all my friends to tell them about The Young ME Sufferers Trust. I said: ‘Okay, my request is the following. I will be running my first race on the 1st of June representing TYMES and I should like any sponsorship / donation in helping these kids get the attention and care they deserve.

‘Moving forward there are several races I have already signed up for and although I do not expect you to support me on every run, if you could do so for at least one of the races it will be appreciated.

Thanks guys
Regards
Fats’

*OKAY MY DARLINGS
see the GIRL run :o)
This is lovely me running
the Yateley 10K on
Wednesday night.*

*Lotsalove
Fats*



Insight

To most young people, a sofa and cushions means chilling out, a short break from a busy life. To a young person with ME it may represent sickness, pain or even a prison. If you are not well enough to join in things, friends can forget you.

We invited our members in the Cardiff area to create photos that symbolised their lives. Now their work is to be displayed. Congratulations to them all. If you live near enough and are sufficiently strong, why not ask someone to take you along? We hope it will help visitors gain insight into the lives of young people housebound with ME.



by Michelle Penny

Exhibition in the Lower Gallery: 23rd August – 1st September



Penarth Arts and Crafts / The Washington Gallery Education Outreach Programme 2004-5

This workshop was designed for young people with ME/Chronic Fatigue Syndrome that are not able to attend school due to their illness. Some of the older participants have been ill for so long that they have not been able to obtain any GCSEs while the younger ones struggle to obtain 3 or 4 through home tuition.

Photographer Suzanne Greenslade visited each of six participants in their homes and they were allowed to produce the work at their own pace. The workshop provided an opportunity for these young people, who are unable to socialise and have become very isolated, to communicate their story to others through the use of visual imagery. The workshop was funded by The Arts Council of Wales and supported by The Young ME Sufferers Trust.

1-3 Washington Buildings, Penarth, Vale of Glamorgan, CF64 2AD.
Tel : 029 2071 2100 Email: info@washingtongallery.co.uk Web: www.washingtongallery.co.uk

Races Fatima has arranged so far for 2005:

Yateley - 10K - 1st June 2005
Yateley - 10K - 1st July 2005
Yateley - 10K - 1st August 2005
London - 10K - 3rd July 2005
Windsor Half Marathon -
25 September 2005
Bupa Great South Run - 10m -
9 October 2005
Billericay Striders Adidas - 10K Road
Race - 6th November 2005

We are so grateful for Fatima's support. She hasn't had ME, she doesn't have any relations with ME, so it's just because she cares.

PLEASE HELP TO SPONSOR FATIMA. YOU CAN GET A FORM FROM www.tymestrust.org or just collect from your own friends and family.

HOW TO DONATE OR TO SPONSOR FATIMA

To sponsor Fatima or hold your own sponsored event, download our Sponsor Form from the Donations page on our website.



*****NEW!*****

Why not donate online? Transactions are secure with PayPal. Use credit or debit card, or your own PayPal account. Just go to www.tymestrust.org and click on the donations page. Thank you.

Things 4

A PRIZE IS WAITING
FOR YOU – TELL US WHO
YOU ARE!

We loved all your *Spot the Difference* competition entries so we managed to find a special prize for everyone who entered! Don't forget to enter again this time. (See page 13 for the new picture.)

A **MYSTERY MEMBER** has sent us a beautifully coloured photocopy of the picture with the correct answer – but with no name.

You coloured the boy's shirt *bright yellow*, the dungarees *bright blue*, the grass was all coloured *green*, the fence and the squirrels *light brown*, the barn and the tree *dark brown* and the running chicken is *two-tone brown*.

We have a prize waiting. We'd love to send it to you.

Send us your name and address.

SEND US YOUR POETRY

We're still collecting. We love to read your poems and we'll publish as many as we can.

Or why not guess the rhymes to finish this poem instead? You can get someone to help - that's not cheating.

**Sitting by my window
I saw a naughty [---]
Who said: Please can you wave at me
Because I'm by my [----]**

**His jacket was a brilliant green
His shoes were brilliant [----]
If you sit by your [-----]
I'm sure he'll visit [---]!**

Prizes waiting.
Don't forget to tell us your name, surname and birthdate, when you send it in to us.

DECORATE YOUR ROOM WITH OUR STICKERS

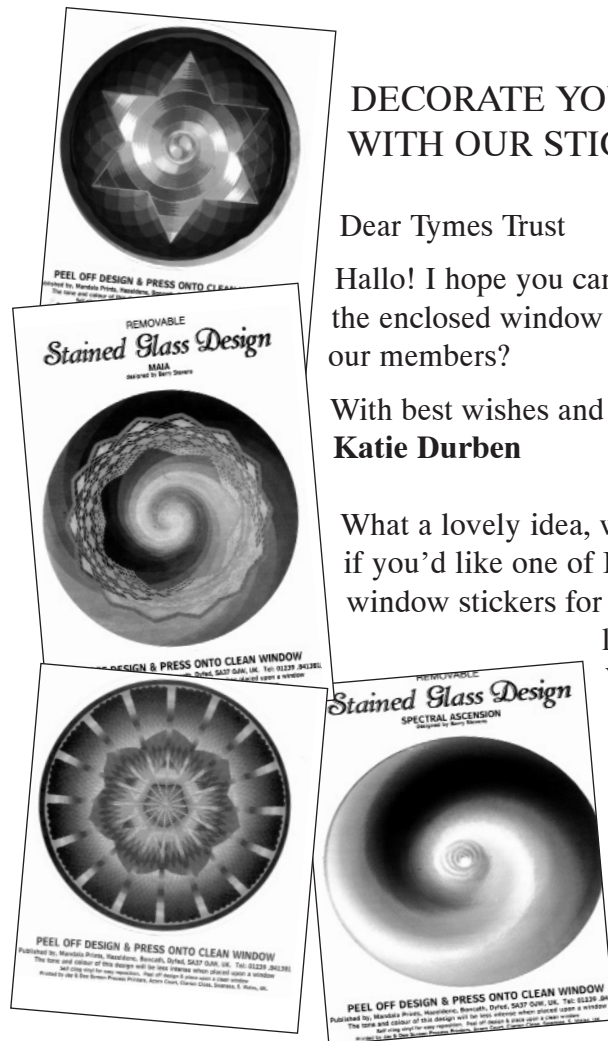
Dear Tymes Trust

Hallo! I hope you can make use of the enclosed window stickers for our members?

With best wishes and sunshine,
Katie Durben

What a lovely idea, we thought. So if you'd like one of Katie's window stickers for your window, let us know.

We've bought some others too, to make sure we don't run out!



HARRY POTTER – PLAYING CARDS FOR MAGIC TRICKS

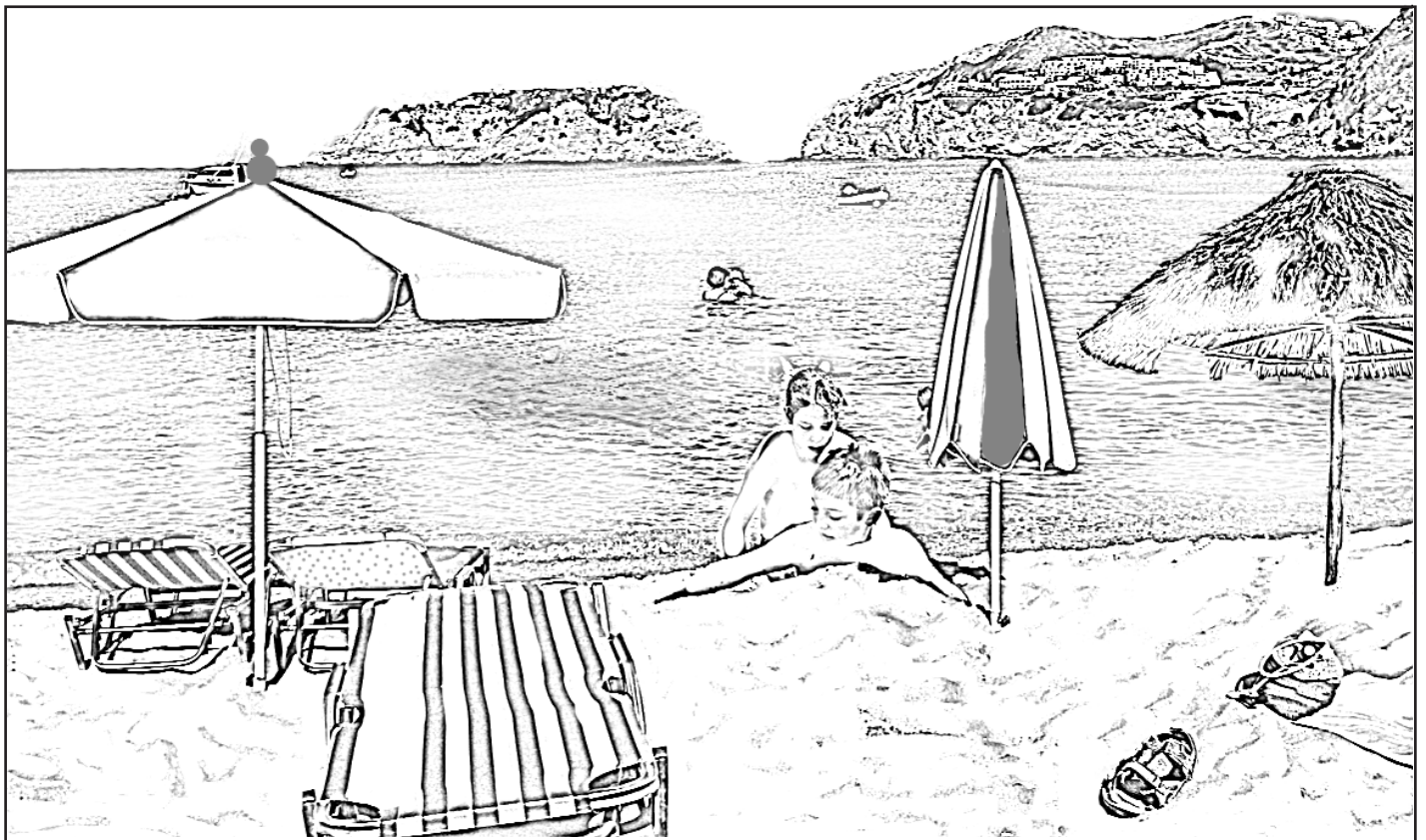
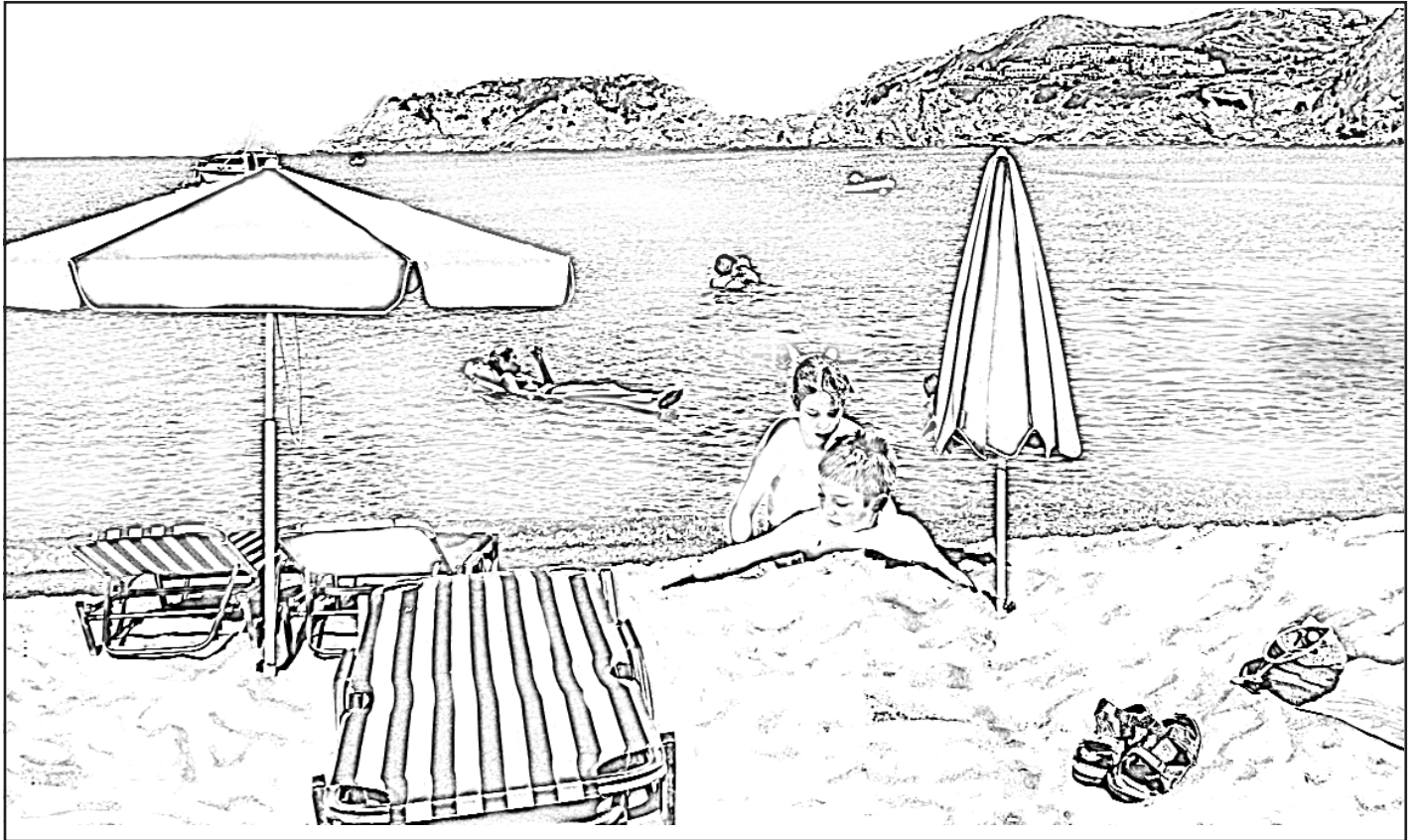
Only a few! To win yours, solve one of these riddles:

- * What do you get when you cross an elephant with a kangaroo?
- * What do you get when you cross a sheep with a kangaroo?

If you really can't solve the riddles, send us a letter or an email telling us why you'd like some magic cards.



U 2 Do



We think there are nine differences between these two pictures. We will send you a prize if you can spot them all. And why not colour the pictures in too? Send your list of differences to: Spot the difference, PO Box 4347, Stock, Ingatstone, CM4 9TE. Remember to include your Name, birthdate and address so that we can send you your prize.

I'VE LOST MY SPARKLE

Dr Darrel Ho-Yen discusses the nature of sparkle and concludes that it's best to use your energy wisely

Recently, a friend mentioned to me: 'I've lost my sparkle.' This phrase struck a chord as I remembered it being said to me over 15 years ago by two patients. One was a 17 year old girl and the other was a 55 year old man. Obviously, time has not affected the use of this description. But what is 'sparkle'?

In discussing this matter with patients, it appeared that sparkle is a product of confidence. It reflected high energy levels so that people can become 'the life and soul of the party'. It was also about the ability to think quickly and produce the witty remark. It allowed the projection of energy so that the individual could 'light up' a group. Without the excess of energy, there was no confidence – *ie* there was no energy to spare - to undertake such activities.

Panic Attacks

When individuals have low energy levels, certain situations can result in panic attacks. These situations are usually where a lot of energy is required. In ME patients, the usual culprits are: driving; long telephone conversations; busy places.

Supermarkets in particular produce a very energy-draining experience. There is so much going on (noise, visual images etc) in the supermarket that it requires a high level of concentration and therefore lots of energy – energy which is already being drained by the journey there and the distance along the shelves.

Generally, where there are lots of people, there is a need to concentrate more and so use more energy. It is one of the paradoxes of ME that individuals who love shopping, parties and busy places suddenly decide that they would rather stay at home and be alone. It is simply their body telling them that they do not have the required energy for such activities.

Understanding 'sparkle'

Simply, sparkle is when you have lots of energy that can boost your confidence and allow you to try anything. Because there is an excess of energy it is

possible to waste a lot of energy in fruitless activities. Is it really necessary to be the life and soul of the party? Is it really useful to be able to 'light up a room full of people'?

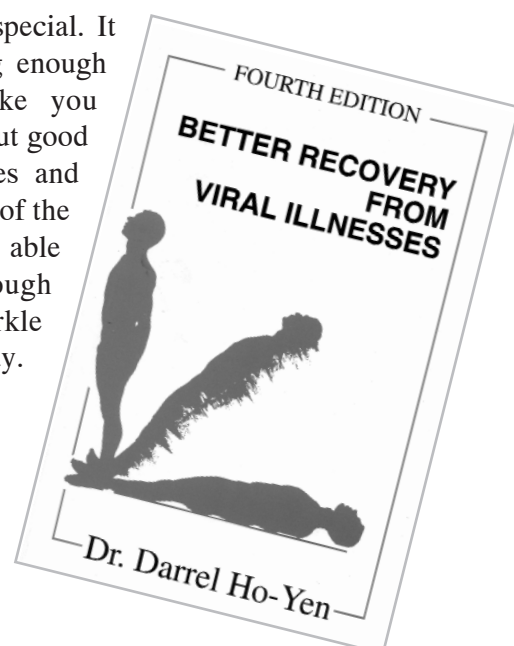
I have always tried to encourage patients to think of energy as money. In my book *Better Recovery From Viral Illnesses* (Fourth Edition) I emphasise that this understanding of energy is vital for recovery.

When patients were well, they had an excessive amount of money (energy) which they could liberally waste on many activities. With ME, there is now very little money. Therefore, it has to be targeted to the things that are necessary for life. Sadly, many of a patient's friends remember what they used to be and frequently encourage them to be their 'old self'. It is important that patients do what they want and not what those around them would like.

Targeted sparkle

When you start to use energy well, you can choose how to target this valuable resource. If you have limited funds, it is important that you choose to spend them on things that really matter.

Instead of having enough energy to light up a large village hall, with targeted sparkle the energy is used to light a candle and to be with someone special. It is about having enough energy to make you happy. It is about good use of resources and an appreciation of the value of being able to have enough energy to sparkle in a targeted way.





Spare Bear?

We still have one or two of Mr Harley's sparkly Brilliant Bears to give away.

If you have lost your sparkle, why not send for one! They are small, pretty, have wings like an angel and you can hang them by your bed.

Only a few left, so email Mr Harley now, using the handy form at www.tymetrust.org

(Or you can phone or write to our usual number and address.)

Don't just assume that you won't be one of the lucky ones. If we have run out, we will find you a little surprise instead!

Recent Research into Exercise and ME – and what it means to you.

This case-control study compared 15 CFS patients to a gender-, age- and weight-matched control group of healthy subjects.

The authors write: 'Because the muscle response to incremental exercise is not well documented in patients suffering from chronic fatigue syndrome (CFS), we combined electrophysiological [...] and biochemical [...] measurements to assess any muscle dysfunction in response to a routine cycling exercise.' All subjects performed an incremental cycling exercise continued until exhaustion. [Don't try this at home!]

The study found that exercise-induced oxidative stress was enhanced.

Dr Vance Spence of the research charity MERGE explains: 'This constricts blood vessels at a time when they should be dilating during exercise. The effect of this would be an inadequate blood supply, hypoxia (lack of oxygen) and ultimately, pain.'

Other abnormalities showed up, including during the recovery period. In this study, the researchers did not continue measuring beyond 30 minutes after the exercise stopped. However, people with ME typically report deterioration during the days after exercise.

The researchers concluded that: 'The response of CFS patients to incremental exercise associates a lengthened and accentuated oxidative stress together with marked alterations of the muscle membrane excitability.

They added : 'These two objective signs of muscle dysfunction are sufficient to explain muscle pain and postexertional malaise reported by our patients.'

How can you use this research?

'Postexertional malaise' put simply means feeling ill after you have exerted yourself. Not just tired but ill.

For those children and young people who are facing disbelief when they describe such an effect, this research is yet another piece of evidence that can be provided for doctors.

The researchers were: Jammes Y, Steinberg JG, Mambrini O, Bregeon F, Delliaux S
Laboratoire de Physiopathologie Respiratoire (UPRES EA 2201), Faculte de Medecine, Institut Federatif de Recherche Jean Roche, Marseille, France

Reference: J Intern Med 2005; 257(3): 299-310

The Countess of Mar in conversation with Jane Colby



Jane: Lady Mar, you are known to be a doughty campaigner on health issues. How did you get so involved?

Lady Mar: I was exposed to organophosphate sheep dip in 1989 and I was relatively successful in campaigning for very considerable tightening up of the requirements such as labelling, protective clothing and so on. There are now far fewer people suffering from OP poisoning than there were. From there I started talking to the Gulf Veterans because they had been also sprayed with sheep dip. There were other things too, such as numerous vaccinations, and I think that their poor immune systems had been totally shot to pieces.

And then I was asked to take up an ME case and I got interested, not because I thought it was pesticide-linked – I've always had an open mind about causation, especially after the experience of the Gulf Vets – but what I was concerned about was these people's experience of doctors.

Jane: You're saying that they were being denigrated?

Lady Mar: Yes, as with the sheep dip poisoning. My doctor went through all the usual things, then all the things that you can get from animals, like brucellosis. Then she gave up on me and decided that I ought to go and see a psychologist because I was clearly batty.

This huge form came from the psychologist – eight pages of A4 – asking me what I thought was wrong with me. So I started to fill it in and put 'I don't know, that's what I went to the doctor for'. It asked

me all sorts of personal questions that you can't possibly put in a family magazine! I thought, this has nothing to do with how I'm feeling. I wrote back and said that if he needed to ask those questions on a form I didn't have any confidence in him and I wasn't going to see him.

By that time I'd also lost confidence in my then GP and I was so fortunate when I changed GPs. He tried all sorts of things – I was in terrible pain by this stage – and he said, 'I know it's not in your head and I know you really have got something physical but I don't know what it is.' And he suggested that I try to find a complementary therapist.

The lady I got happened to be a biochemist who had gone into kinesiology. When she tested me – they're not actually allowed to diagnose – she said, 'I think you've been poisoned.' Well, I couldn't think of any poisons I'd used. It must have been twelve months later that I read a bit about 'dipper's flu'.

Jane: Dipper's flu?

Lady Mar: Yes. That was 1992. I was ill first in 1989. My GP had never been able to understand why I was always sicker in the summer. Well of course it was all the sprays and things. Every time we went to an agricultural show I was sick again, because the sheep had been dipped.

Jane: I believe you were recently at the Royal Show.

Lady Mar: That's right. I thought it was a long time since I'd been exposed to OPs and I'd probably got over it by now. I went to look

at the sheep with my husband and within about two minutes my lips started to tingle and I got a splitting headache. The effect of that 45 second exposure lasted well over two hours.

Jane: Because you've still got a sensitivity.

Lady Mar: Yes. So I now know not to go near sheep that have been dipped.

Jane: So when you heard about people with ME, you thought, they are having the same kind of experience that I did, not being believed.

Lady Mar: That's right. And this is why I started to look into it. It was an empathy with them, I think. We all know our own problems best, don't we? There are illnesses such as fibromyalgia and autism where there is no concrete diagnosis and I keep thinking about the medical profession. They are so stubborn. Unless it's in the book, it doesn't exist. Every time somebody makes a new discovery it takes forty or fifty years for it to be recognised. For example, in the 1930s Multiple Sclerosis was the 'idle man's disease'. So that's how I got into it.

Jane: Research has just found that if you look at the blood vessels you can actually tell the difference...

Lady Mar: ...between Gulf War Illness, ME, and OP exposed people. Yes.

Jane: I don't think many people realise that you have your own farm.

Lady Mar: We have a smallish farm in Worcestershire, about 100 acres, milking goats and making goats' cheese. We have some lovely customers. Many of them can't cope with dairy products but they can cope with goats' milk. The Greeks used to call the goat 'universal mother' continued over...

Campaigning in the House of Lords

In the House of Lords we do not have 'constituents' as such. When I first came to the House in 1975, Baroness Burton of Coventry, who died some years ago, offered me some advice for which I shall be eternally grateful. She said 'Specialise, my dear.'

Without constituents it can be very easy to jump from one topic to another. By sticking to one or two subjects – particularly subjects in which one has experience or expertise – one very quickly gains the respect and support of the House. Unlike MPs, it is better that we do not take on the social worker role, though it did take me a while to learn this. Whilst it is useful to have knowledge of particular cases to give as examples, it is very rarely that any beneficial effect has come from raising individual cases with Ministers.

Now I campaign on the principles: honest science; appropriate medicine; fair social security; suitable education, and recognition of the plight of those who suffer from the group of illnesses said to be of 'ill-defined symptoms'. Of course we all know that the symptoms are well defined – just a bit different between individuals.

As well as my interest in human health I have taken part in and lead debates on animal health and welfare. My concerns about the causation and spread of BSE and Foot and Mouth Disease are well known. Currently a number of us in the House are worried about the spread of bovine TB into the wildlife population.

Jane: And you've won prizes for your cheese.

Lady Mar: We've had gold, silver and bronze medals at the British Cheese Awards. In 2003 we won Britain's best raw milk cheese, because we don't pasteurise our milk.

Jane: You've been heard to say that your milking parlour is cleaner than some hospital wards! There's a challenge to the NHS.

Lady Mar: Yes. Our hygiene standards are absolutely meticulous. We have the Dairy Hygiene Inspector as well as Environmental Health. At our last microbiology test we had 0% for all pathogens. They test the milk and the cheese.

Jane: Everyone who reads this is going to want your cheese! But it's just for sale locally?

Lady Mar: From our farm shop and farmers' markets near Worcester and Stratford on Avon.

Jane: How would they know it was your cheese?

Lady Mar: It would have a label with 'Mar Goats' on it.

Jane: Supermarket goats' milk doesn't taste quite the same does it?

Lady Mar: Well you have to pasteurise supermarket milk. The heat treatment alters the flavour. Our raw goats' milk tastes almost the same as cows' milk.

Jane: It's not so easy for children to visit farms as it was, is it?

Lady Mar: No, it was decided that it was too risky for school parties to go to farms. They can go with their parents though, provided the farmer is willing to show them around. We're always very pleased because we think that young people ought to know where their food comes from.

Mar goats have a lot of liberty. We have a small flock of Black Welsh Mountain sheep and a few free range Saddleback X pigs who are lucky enough to get the whey from our cheese making. They live in the woods in spring, summer and autumn and then come in to be warm and dry in the winter. We also sell our own pork and lamb through our farm shop.

Jane: We've heard from children who've been to farms and wildlife parks and they seem to get a great deal from visiting the animals even if they're still in a wheelchair.

Lady Mar: They get a huge amount from it. There's no harm as long as they wash their hands before they eat anything or put their fingers in their mouths.

Jane: Do you still have limitations on what you can do?

Lady Mar: Yes. I haven't walked up and down the hills on our farm since the early 1990s. I do have a pretty busy life and I can do things in short spurts but I can't sustain them and that's where the walking problem comes in. We have a beautiful farm and I would love to walk out – but it's getting back again!

Jane: We loved the photo of your special goat.

Lady Mar: She is lovely, isn't she? Her name is Mar Secret. Her mum produced her when we weren't looking! The one in the background is her pen mate – Mar Minstrel.



*Mar Secret with
Mar Minstrel*

She arrived when John, who is an accompanist, had a singer here. You will note that both are chocolates. All our brown goats have chocolate names. With a prefix of Mar, what else could we call them?

You Tell Us



Linda Simmons taking Assembly with a copy of Young Hearts

As a school we are delighted to have this book in our school library. It is particularly significant for us, as the author of one of the poems is our own James Tilley.

I was able to share some of the poems with the children in Assembly, and they found them moving and thought-provoking. As James' condition means he cannot be physically present with us in school, this is a lovely way to keep him in our thoughts. Many

of the Year 5 pupils from his class have been writing poetry as a result of looking at the book.

Linda Simmonds
Head Teacher, Honiton Primary School, Devon



James and his head teacher, holding Young Hearts and a certificate James won for The Spider In My Room

The Spider in My Room

He's gone in a crack.
I don't know when he's coming back.
Maybe he's lurking behind my wardrobe
Trying to get out
But will I shout?
Maybe he's under my bed
Trying to sneak up to my head.
He could be behind my desk
Having a little rest.
Finally he shouts 'Yippee I'm out'
I look at him
He's very thin
So I let him out the door

James Tilley



The Seasons

Winter is great, I love the snow
even though it's cold and my hands go numb
No, this is not my favourite one.

Autumn is fun, I love crunching leaves
even though there is rain and the odd sunny sun
No, this is not my favourite one.

Spring is brill, I love the new baby animals
even though I have a small garden I can't run
No, this is not my favourite one.

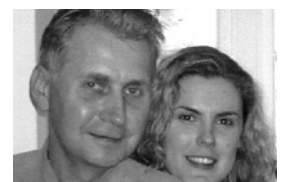
Summer is the best! I love the beach
even though there's been floods and thunder storms
Where's the sun?
YES, this is my favourite one.

Jodie Halliday

Just wanted to say a big THANK YOU for yet another beautiful gesture in my birthday card. Also for the message Jennie sent me which meant a lot too.

Hope the new ME Centre opens the door to a less traumatic recovery for many! On my birthday I had to spend the morning studying Shakespeare... but there was a fire in the college so lessons were cancelled - and I was able to go for a coffee (water in my case) with the rest of my group in the city. Possibly the most eventful birthday ever! **Sazza Holmes**

Toria Bicknell, formerly a member of our Advice Line Team who has also suffered with ME, wants to share her happiness at becoming engaged. She writes: 'Send everyone our love and best wishes. Stephen knows all about the Trust and its significance to ME sufferers.'



SEB'S MANOR



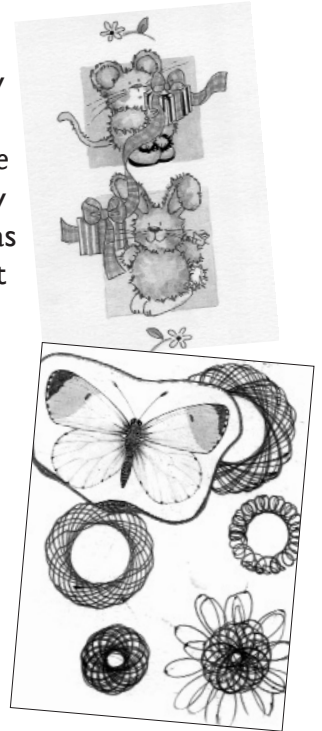
by Sebastian the website spider (find him at www.youngactiononline.com)

Thank you ever so much for my lovely prize for completing *Spot the Difference*. It's really kind of you and was a nice surprise that made me smile.

I'm sure I will have fun drawing with it.

Love and best wishes

Hannah Churchward



Sebastian says:

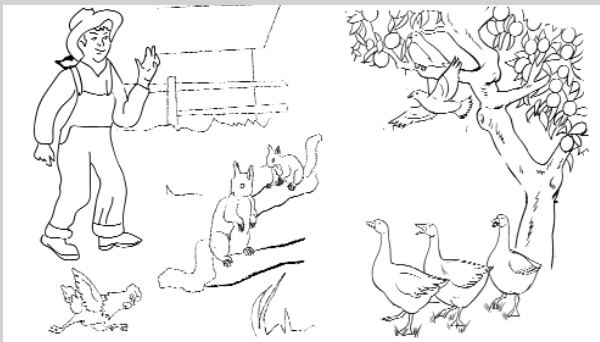
Lots of spidery thanks to kind Jessica Evans for sending us a donation (it was her present money!) because her friend Rhiannon Starr has ME. Here they are together.



When you read this, I'll be on holiday! Yay! Read on....

Seb

PS I've been put in charge of choosing the prizes that go to people! So why not enter 'Spot the Difference'?

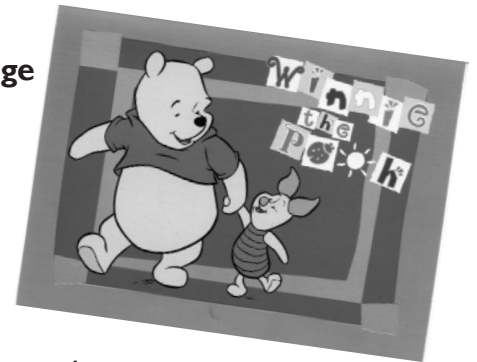


Picture used in last *Spot the Difference* competition, why not colour it in?

Dear Seb

When I receive VISION I always turn to your page first. Anyway, I was just wondering whether you wanted to come on an adventure. I am going on holiday in August and I was wondering if you would like to come too. There would be loads to do for a spider and of course you would be able to eat as much as you like!

Love from
Kadie Plumridge (14)



Dear Kadie

I am graciously accepting your esteemed invitation to share your summer holiday. When do you go?

I won't pack any bags as I travel light and anyway I am relying on you to provide anything that I need?

I am very impatient to set out on this adventure. I nearly got into the envelope with this letter!

I hope you can take pictures of us on our holidays that I can publish on my page. Everyone wants to see what we get up to – and what we eat!

Love, **Seb**
Xxxxxxx

TRUSTY SAYS : 'WOOF! My best grown up letter WOOF!'

Here's my choice of parents' letters! Jane Colby visited ME Support Norfolk, one of our Partner Groups, and they recorded her talk so you can watch it! Ask for the DVD.

Here's what Claire Wade's mum wrote:

'Thank you so much for coming all the way to Norfolk and giving us such an interesting afternoon. It was really nice to meet you and to thank you personally for all you have done and are doing for us all. Thank you again. Best wishes, **Anita Wade**'



Just wanted to say a big thank you for my 18th birthday card. It was a lovely surprise to receive it. I have a special box to keep all my 18th things in and I am saving your card in there too Thank you.

It was exciting to see my letter in the latest magazine and Fudge was very excited to learn that Trusty is the only hibernating dog in the world and was really happy to hear he had woken up and is looking forward to seeing him in the future.

I hope you have found a home for all your sparkle bears but if there is any who have not been adopted Fudge and Max said a sister would be very nice but I don't mind if they have found homes with other families I just don't like to think of them been lonely.

How's Seb? Has he been to stay anywhere nice lately?
Send him our good wishes please

Love from Cheryll and Fudge and Max

Seb says: I still remember my wonderful holiday with Cheryll! And we did send her a sparkle bear.



Hi my name is Megan and I have a rest bear called Choc R. He keeps me company when I have to rest but he gets very lonely when I am not resting. Please could you send me a Brilliant Bear to hang out with him and keep him company? Thank you. Love from Megan....

....Thank you for my Brilliant Bear! I was very pleased when she came through the post. Rest Bear is really happy with his new friend Brillette as you can see in the photo. Thanks again.

Love from
Megan



Dear Seb

Just a little picture I coloured with help as I'm not well enough to write. Hope it brightens your wall.

Lots of love
Emma Gray
xxx



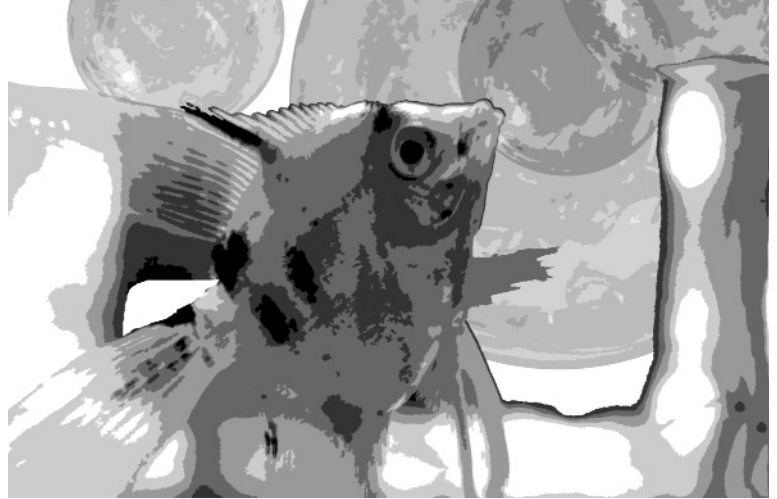
Seb says: I've still got lots of my treasure left. Send me a little card or a picture for my page and I'll send you a surprise from the Treasure Chest.

Here is a poem I wrote about my angel fish called bubbles. I wrote this one day when I was feeling very low!!

I have an angelfish called bubbles,
who always bosses the other angelfish and gets into trouble,
His eyes are like gold sequins,
and they are shiny and bright like a new pin,
He is black, silver and yellow,
and yes he is a very graceful fellow,
He is the best fish I have got,
He is much better than my other lot.
He likes to hide in the weed,
and he is always ready for a feed,
He swims around all day,
what more can I say!
except he is my angel fish called bubbles!

Hayley Rastall

From The Heart



In my dreams
I dance in shadows
when no one's looking,
delirious and free
soaring through stars
carelessly twirling,
my feet in perfect rhythm
with songs in my mind,
in my dreams

Charlotte Bibby

A LETTER FROM.... KATIE EVANS

I thought I'd tell you about myself. I'm 15, I live with mum and dad, my sister Julie, 13 (who is now my best friend) and brother Alun, 10.

They also have ME. My older brother Andrew had ME about 8 years ago and he is now at University. My older sister is the only one not affected by ME. I've had ME for about a year and a half, I suffer from terrible headaches and am not able to go to school.

The ME leaves me with memory problems, now what was I saying oh yeah.... I write poems to show my feelings and since I've been ill I've written 8 poems, one called *Year of Hell* that was published in

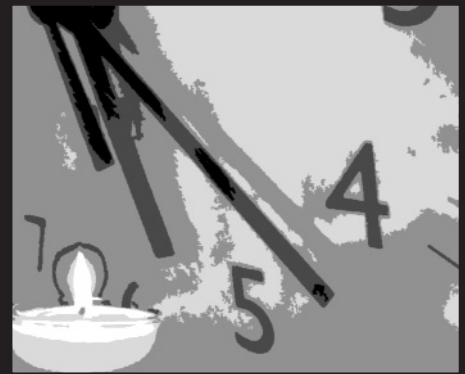
the book *Young Hearts*. The book was wonderful and after I read the poems of others I wrote one called *So There!* After that I also wrote another one called *Little Candle*. I put in a copy for you hope you like it. Thank you very much.

Good wishes, Luv **Katie**

Katie's poem 'So There' was published in VISION (March/April issue). If you would like to write us a letter, you can send it by post or email (like Katie) using 'Contact Us' at www.tymestrust.org

Little Candle

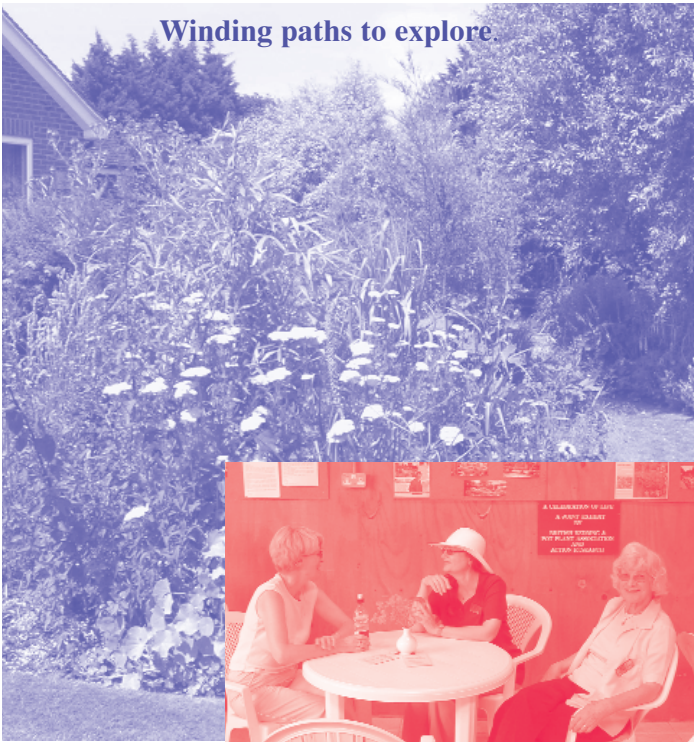
I sit in black with one little candle
looking into the flame
Waiting!
Waiting!
Waiting!
For what? I don't know
I see pictures in my head
memories of friends
laughing playing singing
but now they're gone
the red, yellow, blue sky and green grass
have faded, been replaced
with sadness and loneliness
I want it back!
I'm working hard to find it!
Climbing up and up but
Then just sliding back down
Further!
Further!
Further!
The candle's getting smaller
The light fading away
Time is out of reach
I'll never get it back!
The clock is ticking but the
hands aren't moving
Tick Tock!
Tick Tock!
Tick Tock!
I hear nothing, not a whisper
Not a sound
It's gone, disappeared
Along with the care
Why I don't know?
Loneliness sinks in
Makes a new home in the black
Digging
Deeper!
Deeper!
Deeper!



A few minutes of light left
In the dark cold space
The candle is going out
Not much time left
My dreams are drifting into space
I will find them but
For now I'll wait
The light has
Gone!
Gone!

By Katie Evans

Winding paths to explore.



The Young ME Sufferers Trust Open Day Westlands Garden and Nursery

Glorious sunshine made the Trust's annual Open Day at Westlands Garden and Nursery an unforgettable occasion. It also raised much needed funds to continue the Trust's services for children and young people with ME and their families. Owners Keith and Sally Player specialise in unusual hardy plants and run a garden design service. Visit them right throughout the summer.

Parent Angela Marrow meeting with Trustee Margaret Ross and Jane Colby in the Westlands tea-room. Volunteers served speciality home-made cakes and scones to our many visitors.



Jane relaxes in a quiet bower

Early arrivals investigate the gardens and lake



Children love the donkeys



Resting by the lily pond

Would you like a personal invitation to next year's Open Day? Write to: Westlands, Chalk Street, Rettendon, Essex, CM3 8DE.

Or email via

<http://www.westlandsnursery.co.uk/contactus.html>



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 ICD 10 G 93.3