

The Young ME Sufferers Trust
March/April 2005
£2-95

Wision

DEAR SHIRLEY

Your prize winning
letters to Shirley
Conran OBE

MEET OUR NEW PATRONS

The Countess of Mar
Barbara Windsor MBE

PUSHING THE BOUNDARIES IN ME/CFS

Jane Colby kills the
psychological myth

THE BRIEF

Central pullout:
Featuring the RCPCH
Guideline for
Paediatricians



SEB'S TREASURE CHEST GIVE-AWAY!

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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

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Our Patrons



Lord Clement-Jones
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Earl Howe



Shirley Conran
OBE



Lady Elizabeth
Anson



The Countess
of Mar



Barbara Windsor
MBE

VISION: THE PROJECT

I am delighted to write to you about progress in our *Vision Project*, which gathers momentum all the time. This issue of VISION is brimming with comments and feedback.

Part of the Project is to make our publications available free at www.tymestrust.org One of the latest, *Whispered Words*, is about young people with severe ME. The first comment we received was: 'I am much impressed by this document – I had not seen it before. I just wish I could physically give it to all GPs and paediatricians.'

Our full publications list is in *The Brief*, the information pull-out that Jane Colby has been asked to produce for each issue of VISION.

Another part of the Project is to step up campaigning. The book *Young Hearts* is playing a key role. The present Prime Minister and the Leader of the Opposition wrote to us:

'I am pleased to support *Young Hearts*, which will help improve awareness and understanding of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) [...] Much of the distress surrounding CFS/ME is caused by difficulties in the recognition, acknowledgement and acceptance of the condition and its impact.'

Tony Blair

'The most inspirational poetry comes from the heart of those who have a story to tell. Those who have contributed to this collection have stories of courage and perseverance. I am sure their poems will help the friends and families of other young people with ME; they will raise awareness of ME itself; and they will provide inspiration to all who read them.'



Jade Scarrott

'It was the courage and vision of Jade Scarrott which made *Young Hearts* possible. Through this collection of poetry, Jade's life too will now continue to inspire future generations.'

'Tymes Trust provides much-needed practical support for children and young people with ME and

their families, and I pay tribute to its work in overseeing this valuable project. I am sure the Trust will continue to go from strength to strength.'

Michael Howard.

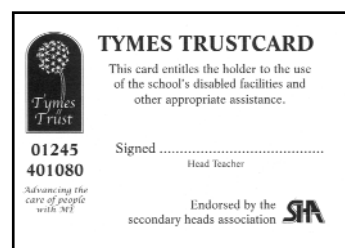
And Jade's MP writes: 'It's very fitting indeed that Jade is to be honoured by way of a Young Hearts Day on 29th November.' *James Plaskitt*

Another aspect of the Project – our biomedical research study with MERGE – prompted a query from 26+ member Kirsty Hinton. As a result, we asked Dr Vance Spence to explain in further detail for this issue of VISION.

Recently, Tanith Parkes, 14, emailed us: 'Thank you so, so much for the Tymes Trustcard. It has been so beneficial for myself in the classroom,

and the information has helped past and present teachers understand exactly what is wrong with me as it was very difficult to explain before. Since activating the card at my school, another student also with ME has been very interested in applying for a card, so on her behalf I am asking for an application pack.'

This prompts us to ask all Trustcard holders to send feedback in case there is anything further we can do. That is what we are here for.



Planning ahead, I hope to meet many of you on Sunday 10th July at our Summer Open Day. We shall be at Westlands Nursery and Gardens in Chalk Street, Rettendon, Essex. Tea, cakes, a peaceful country garden to rest in. Make a note of the date!

Keith Harley
Chair of Trustees



Meet Our Patrons

I am delighted to welcome Margaret, Countess of Mar and Barbara Windsor as new Patrons of the Trust.

Margaret Mar has been a fantastic champion for people battling with the medical establishment and the government to establish particular conditions, such as ME, Organophosphate poisoning and Gulf War Syndrome and the causes of those conditions. We are proud to have her on board as a Patron.

I am also delighted that Barbara Windsor has joined the Patrons. Barbara is known by all and loved for her work. Having suffered from an ME-like illness herself, she is very sympathetic to the difficulties faced by our children.

Lord Clement-Jones CBE
Founder Patron



Barbara Windsor MBE

When Barbara joined us, she emailed us: 'I am thinking of you all and continue to send you all my love and support for the coming year.'



A Letter From Shirley Conran OBE

Do you have a penpal? I do! I am so lucky because my penpal is Jane Colby. I phone her when I can't stand it a minute longer, and she phones me when *she* is down in the dumps (which is rare). Luckily, we are never 'down' at the same time. Jane reminds me

of everything that is going well in my life, of everything I have to be grateful for. She also reminds me that the black fog will pass.

If you haven't got an ME penpal, why not post your request using the Contact Form on the Trust's website? State your age and nearest town, because at some future date you might arrange a meeting, if you don't live too far away! It was a very happy day when Jane Colby eventually visited my home in London.

Best wishes
Shirley Conran

The Countess of Mar

I am delighted to have been asked by Jane Colby to become a Patron of the Tymes Trust. I have watched from a distance all the hard work that you all put into ensuring that your organisation represents your views.



Your achievements in the promotion of your educational as well as your physical needs are outstanding. It is far too easy to forget that young people who are ill must not be left in an educational backwater; nor must you be forced into activities that you are unable to sustain, mentally or physically.

There is still a lack of understanding of the effects of ME. It is my objective that, with your help, we can change the culture that says that ME is 'all in your mind'. I look forward to working closely with you.

In The Spotlight: What is the ME Alliance, what is it doing and why do we belong?

In 2002, the Dept of Health published a report by the Chief Medical Officer's Working Group on CFS/ME. The Young ME Sufferers Trust was a member of the Group along with other ME charities, six of whom now form the ME Alliance.

The Trust took a prominent role in producing Chapter 5, on children with ME, which made excellent recommendations. We published *Key Quotes* which you can find at www.tymestrust.org/tymespublications.htm

Any consensus document comes about by joint working. It is time-consuming and very hard work. We know from experience just how hard it is to obtain consensus on anything!

In 2004, after speaking in the Scottish Parliament on the dominance of psychiatry in ME – and the need to challenge this – the Trust met with the other Alliance charities to plan the future. The point of an Alliance is to stand together over vital issues. We suggested a joint campaign for ME Awareness Week 2005.

The campaign will target the need for early diagnosis. Psychiatric bias has traditionally discouraged doctors from diagnosing ME on the theory that patients may stop trying to get well.

Our campaign will push for people to be told what is wrong as early as possible, so they can be helped.

The Alliance met on the same day as the funeral of Jade Louise Scarrott, and we began with a two-minute silence in her memory. By the end, we had all drawn up an Agreement.

Point (c) of the Agreement will be particularly important. It is no secret that we all have different policies, approaches and opinions. Doing a joint project was never going to be a pushover. But many young people and adults

belong to several ME charities and wish us, whenever possible, to use our combined strength for the good of patients.

Let it not be said that we ignored their requests.

The ME Alliance Agreement

The Common Aim is to secure improved recognition, care, support and information for all those whose lives are affected by ME/CFS/PVFS

The Objectives are to:

- a) agree public statements on common issues
- b) agree and plan joint campaigning activities where appropriate
- c) recognise issues on which members agree and resolve or recognise differences in policy or approach
- d) to promote the collection and exchange of information on ME/CFS/PVFS
- e) to establish and sustain a high standing for the Alliance
- f) to identify issues of mutual concern and pursue agreed courses of action
- g) to secure increased recognition and understanding of ME/CFS/PVFS
- h) to seek to inform and influence policy-makers about the needs and circumstances of people with ME/CFS/PVFS

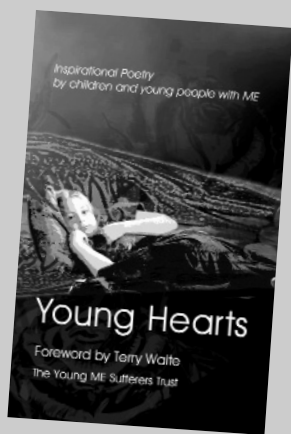
The Alliance members wish to foster a spirit of co-operation and mutual encouragement among member organisations for the good of the cause.

To help the ME Alliance fight its campaign in ME Awareness Week, please get in touch soon. Tel: 01245 401080 or use the Contact Form at www.tymestrust.org

I have just received my copy of *Young Hearts*, a book of poetry by youngsters with ME, compiled by the The Young ME Sufferers Trust. I'm overwhelmed with what I've read so far. This book is amazing and the youngsters express so much so well. I think anyone working, caring for, or living with ME should read it. I want to say a very big thank you to all who have made this book possible.

Janis Thompson

Reprinted with kind permission from FreeMEuk



Excellent launch event – covered loss, sadness, joy and above all – what beauty can come from tragedy...

Diane Newman

Cambridge Neurological Alliance

Last week my son had the biggest grin on his face I have seen for a long time. Thank you so much. Seeing his poem in the *Young Hearts* book has made his year, if not more, and for me.

I cannot describe what it was like to see him so happy and pleased that he had achieved something. His little face was a picture Jane, and just to make you smile, he thinks he should autograph his books for his grandparents 'because that's what writers do, don't they mum!'

Can you please thank all concerned and pass this on to Jade's family to thank them for allowing such a wonderful dream to continue.

Through this book Jade has touched many hearts and I am sure many more to come. James' home tutor is going to order a couple of copies for the home education library as he thinks it is a wonderful book, well written, presented, and has several uses in the library for others, pupils and teachers alike.

Caroline Dugdell

What you think

Just a note to say that although I personally know nobody who suffers from ME and until recently had very little idea of what it is, or anything about it, I work with Jade Scarrott's grandfather and following her tragic accident, bought a copy of the *Young Hearts* book of poetry. Reading the poems has made me realise how debilitating the illness is and how inspirational the poems are. My congratulations to all concerned with the book, especially the children and young people who wrote the poems.

Michael Wincott

We were really delighted with this lovely book. Sheena is very pleased to be a part of it, congratulations to everyone involved.

Eilidh Hewitt

Very many thanks for the Christmas card and birthday card! I am a relatively new member so these were my first cards from you and I really appreciated them.

As well as being diagnosed with ME in March 2004 I am hypothyroid and have also had to fight the clinical depression that developed. It will not get the better of me! One way for me to look after myself better is to go back to my arts and crafts; I enjoy them so much. I hope all of you are keeping well; you do an amazing job and I know all you do is appreciated by young and old alike, but I can't imagine the isolation of the younger people with ME.

Jessica Wilkinson



From Jessica's poem on Hope, written on her birthday.

Like the dove that flies and swoops through the air,
A free spirit swirling in the sky,
My hope is precious and free
And whatever treacherous paths I have travelled
NONE can take away that hope from me.

Thank you very much for the *Young Hearts* book, it came yesterday and it was so nice to read other people's feelings on being ill and how they deal with it - it's nice to know I'm not alone :) Also thank you for including some of my poems in this book, it was good to see them in a proper book. I think the book looked lovely with all the illustrated pages.

Rachael Marshall

Dear Jane and all your wonderful colleagues at Tymes Trust.

Thank you for the new style magazine (BRILLIANT) and for the pull out facts (BRILLIANT) and for the fact that sensible research is now happening (BRILLIANT) and for the emotional and inspirational boost you give us, stuck in the 'ME box'.

We enclose a small donation and some prayers this Christmas for you all in your work.

Bernadette Ward and Felicity (ill for 7 years now age 18)

I was especially delighted to read about the first biomedical research funded by MERGE and The Young ME Sufferers Trust. Well Done to you all - what a brilliant idea.

Gill King



Thank you for the birthday card which you sent to me. It is nice that you think of children with ME always.

Jennifer Simpson

Our copy of *Young Hearts* arrived today. What a *BEAUTIFUL* book! The foreword by Terry Waite, and introduction by Jane, are an inspiring and profound way to start the book. Kerry-Ann's cover design and illustrations are totally enchanting!

Katie is thrilled and humbled to be part of this touching and inspiring book and will write to you as soon as she is able to. She was very moved by Kerry-Ann's illustration that accompanies her essay; it expresses the essence of her essay SO well... it is so 'Katie' :) The poetry of the other contributors also had a profound effect on her...

Maria from South Africa

Dear Jane

When *Young Hearts* arrived, I was absolutely thrilled! It is such a beautiful book and so special to be part of it. All the contributors' work is very touching and inspirational to me. Kerry-Ann's illustrations are all beautiful - and the one that accompanies my essay is PERFECT! It captures the mountain (and myself) so well. I feel very happy and humbled to be part of this wonderful anthology. I hope that it has touched other young ME sufferers as much as it has touched me.



I also enjoyed VISION. The new name is very apt, because the magazine gives one a vision of other people in similar situations; and it provides hope and inspiration. The photos on the back cover of you and Kerry-Ann working with *Young Hearts* were most enjoyable; I think you look like an Arthur Rackham drawing in your long dress :)

Thank you very much for the lovely Christmas card: it is so cute.

love
Katie



Dear Shirley

We promised we'd publish the best entries for the Shirley Conran writing competition. Here is our choice for this issue.

Every moment of my day, however long I am awake for, I try to appreciate the small things in life. One thing that I really take pleasure in is just gazing out of my bedroom window.

I often spend at least ten minutes in the morning just taking in the scenery before I have to get up and do some work. Sometimes I sit for even longer in the afternoon.

I am fortunate enough to have a raised bed that comes to just under my windowsill, so I have a fantastic viewpoint. I always sit so that I cannot see the eyesore of the busy A14 and the bright red and yellow blob of McDonalds, and then I just simply look.

I love Spring as every morning brings a change in my little square of scenery. New flowers in our border that I didn't even know had been planted, or maybe just a newly uncurled leaf, I try to take them all in. There are always new colours to be seen and new creatures about to be smiled at.

I enjoy watching the vast variety of birds feeding on the patch of grass outside my house. If you look for long enough, you can see they all have their own personalities; it is wonderful to see.

I have also always valued the fact that I have a herd of cows living on the hill opposite my window. I am sure that they are not even aware of my presence, but I really appreciate their help in deciding whether I can go outside and sit in the garden! Today they are undecided, like me, as half are up and half are lying down, so I think I'll stay put! I think it's the joys of April showers that's putting them about.

However, if I can't enjoy the serenity of my back garden, I always have my cat to keep me company. He loves to come and sit on me of an afternoon whilst I rest. He sits on my lap and snuggles into my blanket. I can sit for hours just watching his furry body heave gently up and down as he sleeps. I can take in his perfectly beautiful, yet endearingly wonky face and his whiskers quiver as he dreams. Who needs an electric blanket when you can have a fur one?

continued ...



MEMORIES

Then I spy a flash of red. The Postman! He is a little unpredictable time-wise lately, but his arrival never fails to make me smile.

Whether he brings me anything or not, I always find pleasure in looking out for him. Although I am convinced he sometimes plays games with me and tries to creep up and put things through my letterbox without me noticing!

The most wonderful thing has just happened. A huge, but lovely bumble bee has just buzzed up to my window to say 'hello'. A perfect example of the things I cherish; those unexpected surprises that make you smile.

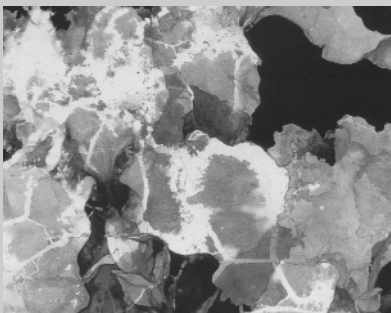
And now the sky is letting out another April shower, our resident blackbird is singing his cheery song and it is about time I ended this letter. I hope you have enjoyed this little snap-shot of the things I appreciate and value.

Take care.

Love

Bethany Reid

16 years old



Love From ...

Thank you for my 15th birthday card. It was a very strange day as I couldn't remember what a birthday was. I only remember the day I am in. I did this poem before my memory became so bad (Mum wrote this for me.)

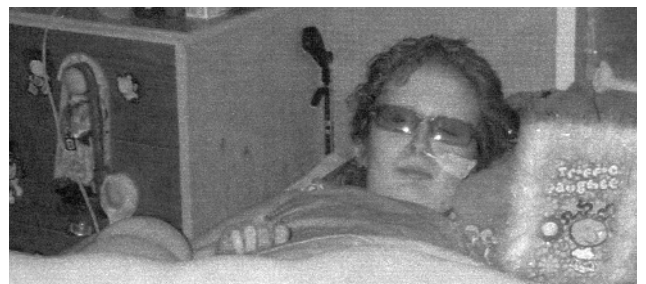
Feel the wind in my hair once again...
Would like to see the sky
blue and cloudy when you look up high.
Even feel the rain on my face once again.
Feel the warmth of the sun.
Look at hills and mountains
some that reach the sky.
See birds and bees fly around.
Walk on the beach.
Feel the sand in my feet
go into the water knee deep.
This would be wonderful.

Most of all I see the light
when it enters my room
let it hit my crystal
sparkle colours around my room.
These are things you miss
and even more you forget
as it has been so long
it's hard to remember
what these things are like.

This is the sad side to ME
it affects your memory.
I have forgotten most of these things,
what I used to know and see.
Sad this has happened to me.
I hope these memories
will come back to me.
How happy I will be,
Be able to go outside and see
these memories for real.

Jade Smith

*We are grateful
when our more
severely affected
members are able
to share their
experiences with us.*



Meet The Team



Kerry-Ann invited to take part in Platform 5

In September 2004 I was asked if I would like to participate in an exhibition at Bury St Edmunds Art Gallery. Only having done one exhibition before with my university, I nervously agreed. However, that nervousness was replaced with excitement as I found out more about the exhibition.

Platform 5 is Bury St Edmunds' Art Gallery's fifth annual display of up and coming artistic talent, with the aim of helping these artists launch their careers. Only 24 hand picked art graduates from five different counties were chosen to exhibit their work and I was amazed and excited to be one.

On the opening day the artists were invited to a launch celebration where we were able to meet the other artists and take part in some delicious munching of food. I also found out that 'ONE' railway network is supporting the exhibition by displaying limited editions of our original work on certain routes.



Kerry-Ann Edge

Art Workshop Report

In January the Young ME Sufferers Trust invited its young members in and around Cardiff to join an Art Workshop especially arranged for young people housebound with ME.

Run by The Washington Gallery in conjunction with the Trust, the Workshop is being led by photographer Suzanne Greenslade who herself suffered from ME for many years. Suzanne has visited all the participants in their own homes and they have already embarked on the project.

They are now making a 'visual diary' about how ME has made them feel and how it has changed their lives. Suzanne is encouraging them to have fun with the diary as well as to use it as a chance to let out any frustrations. Ways are being found to help the really poorly to join in.

Suzanne says: 'This is *their* diary so there is no right or wrong way to do things. These might be diaries in book form, pictures on a wall or freestanding objects with photos attached to them. At the end of the project they will be able to discuss how their work can be exhibited at the Washington Gallery in Summer. Their friends, school or college are going to be really impressed!'

Suzanne has exhibited her own work internationally and we have previously featured some of her photographs in *Tymes Magazine*.

The Washington Gallery is just outside Penarth, by the sea. Their website is www.washingtongallery.co.uk The date for the Summer Exhibition is not yet fixed. To find out, telephone 02920 712 100 or email info@washingtongallery.co.uk



Suzanne Greenslade

Insight

**Love is a word we use too little
With only four letters which
Takes a second to say.
If only I had used it once
At least every day.**

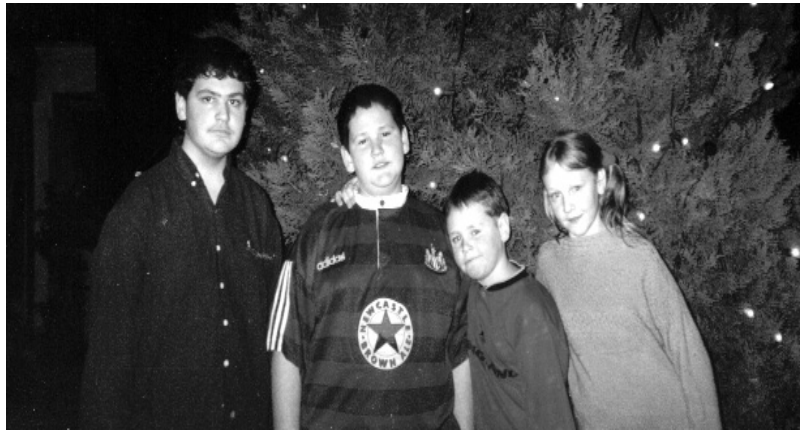
*From a poem by Joseph Anthony Scarrott,
brother of Jade.*

When someone has ME, it is easy for them to feel of little use. All the things they used to help with, they can no longer do. Parents would do anything to make their children well; some tell our Advice Line Team that they would rather go through the pain themselves than watch their children suffering.

How important it is, then, to express our continuing love for brother, sister, daughter, son. Love can have a real influence on healing because it reduces that

If we want someone to know they are valued and loved for *who they are*, not for what they can do, they need to be told so.

terrible, debilitating load which comes from believing that our role has gone and we have nothing to offer.



Joseph Scarrott, second from the right

If we want someone to know they are valued and loved for *who they are*, not for what they can do, they need to be told so.

Joe says: 'Hopefully my words will help others to realise how important it is to express emotion while you can. I found that from Jade being at home more, due to her illness, it gave me a chance to spend more time with her than I would have if she had been well enough to attend school. Obviously, we weren't given enough time! But I'm still glad that I had the years I did with her than none at all.'

From Our Partner Groups

Warwickshire Network for ME

I just wanted to say thank you for the invite to yesterday's *Young Hearts* launch. Although it was very much touch and go until the eleventh hour whether we would actually get there, I'm so glad that we did.

The book is beautiful and a credit to all those involved. We bought 3 and will be recommending it to all and sundry!

We were both extremely impressed by Jane's address and that of Terry Waite, but we were in awe of the dignity, courage and determination displayed by Jade's mother Karen.

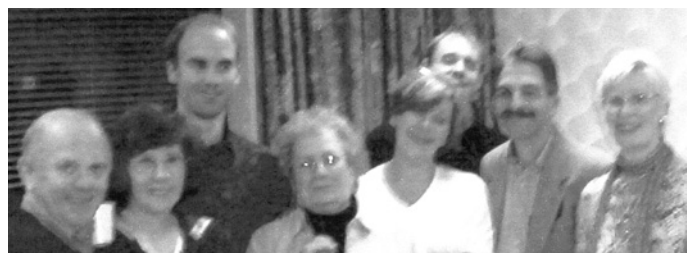
Keep up the fantastic work.

Duncan Cox

Solihull and South Birmingham ME Support Group

We would like to congratulate you and say thank you for all the excellent work you have done this past year. We don't know where you all find the time!

Jennifer Griffin



Things 4



CAN A COMPUTER BE PSYCHIC?

Mark Colby says: 'How else could it get this right?'

Remember the Animal Vegetable Mineral computer game? You think of an object, go to www.20Q.net and the game asks you 20 questions.

You have to give it one clue – you must tell it how to classify the object. Here's what the computer asked Mark and what he answered.

1. It is classified as 'other'. (That means it's not an animal, or a vegetable, or a mineral.)
2. Is it flat? No.
3. Is it usually colourful? No.
4. Does it bring joy to people? No.
5. Is it smaller than a loaf of bread? No.
6. Does it make sound? No.
7. Do you use it in your home? No.
8. Is it something you can purchase? Yes.
9. Does it have a handle? No.
10. Is it larger than a microwave oven (or bread box)? Yes.
11. Is it used by the police? No.
12. Is it tall? Yes.
13. Can you open it? No.
14. Is it straight? No.
15. Can you hold it? No.
16. Does it break if dropped? Yes.
17. Can you buy it at a store? Doubtful.
18. Is it made of metal? No.
19. Is it man made? Yes.

We couldn't guess this at all.

But the computer said: 'I am guessing that it is a gargoyle?'*

Mark exclaimed "YES, IT IS! Unbelievable."

**A gargoyle is an ugly face they used to put on churches because they thought it would frighten evil spirits away.*

NOBODY WON MARK'S 20Q - so now you can all take turns to borrow it!

Mark bought a special 20Q game for you – a funky blue one – that you hold in your hand. You can play it in bed, or hanging out with friends, or with all the family. Parents can't keep their hands off it.



Mark is waiting to send it to the first family who writes in. Get writing quick!

SNAP OFF A SNAP!

Do you take photos? We do. You can use a digital camera and delete the ones you don't like. Or use a disposal camera that has one film – they're not very expensive.



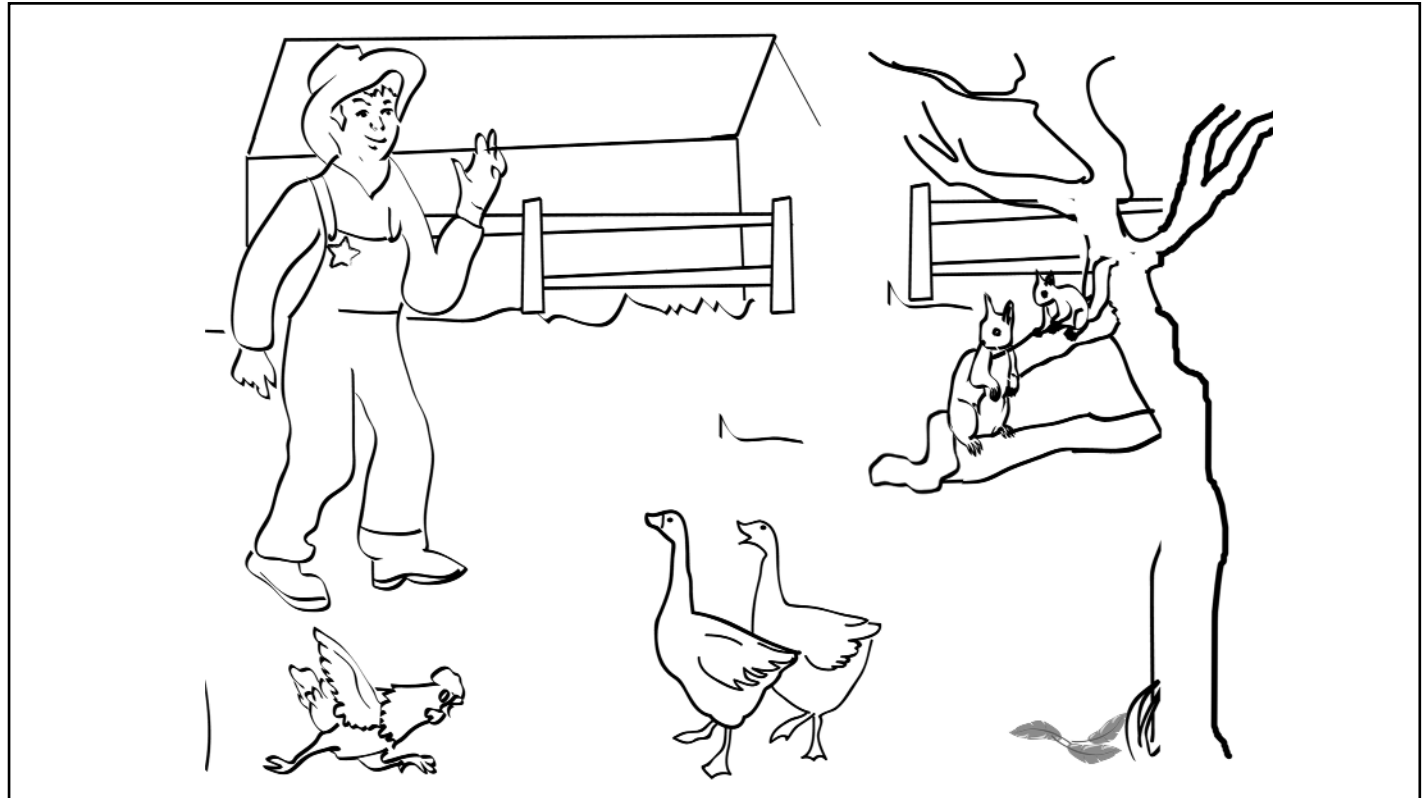
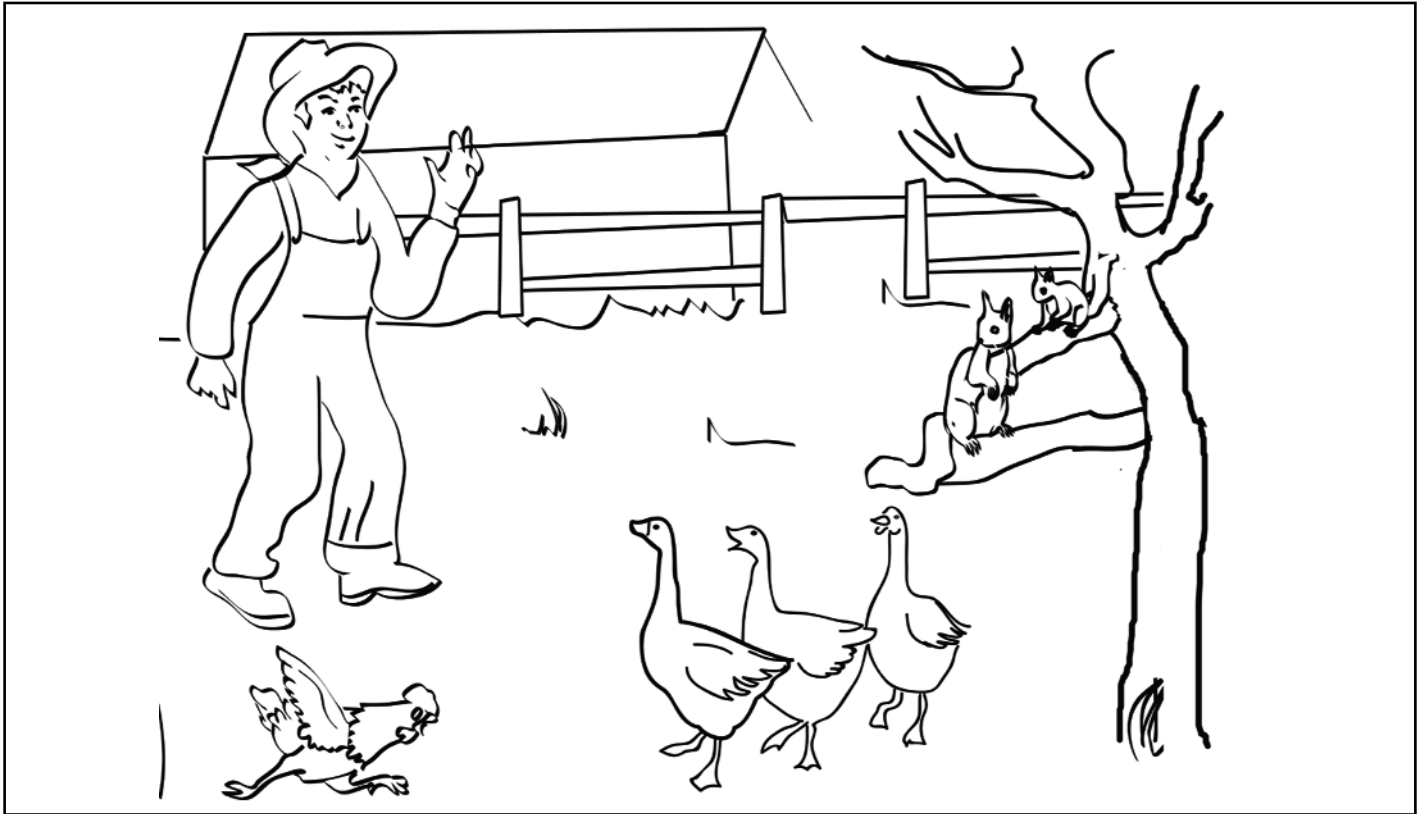
Michelle Cross with her sister Abigail and their parents, at the Essex Record Office, receiving a cheque for the Trust from Essex Community Foundation.

Also pictured, Chair of Trustees Keith Harley and Jane Colby.



Can you send us a photo for VISION?

U 2 Do



Spot The Difference

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

First Ever Biomedical Research on ME in children

In the first issue of VISION we announced the first ever biomedical study to be carried out in children. The Young ME Sufferers Trust is co-funding this study with MERGE and a separate contribution from SEARCH ME.

The Trust has received a letter from Dr Gwen Kennedy, a principal researcher with the Vascular Diseases Research Unit at the Institute of Cardiovascular Research who will be carrying out the study.

The institute is a division of Medicine and Therapeutics at Ninewells Hospital and Medical School, Dundee. Dr Kennedy writes enthusiastically about the ‘forthcoming project on Biochemical Aspects of ME/CFS in Children’ and the ‘final published scientific papers and scientific presentations at local or international conferences that may result from the study.’ She is delighted that this project is to go ahead.



Shortly after reading our first announcement of the study, 26+ member Kirsty Hinton asked more about it. She was interested in why it is important to study children, and why we need to discover whether the same abnormalities exist in children as those found in adults. So Jane Colby talked again to Dr Vance Spence, Chairman of MERGE.



Dr Vance A Spence is Senior Research Fellow, Cardiovascular Research Institute, Department of Medicine, University of Dundee

Jane: You’ve told us that work you’ve already done shows that a persistent infection of some kind might be what causes ME?

Vance: Yes. The results suggested that ME might be caused by a continuing challenge to the immune system – and that challenge could be viral.

Jane: So can you tell us a little more about why vascular research is important?

Vance: Of course. I am often asked why we carry out research in the Vascular Diseases Research Unit. After all, ME isn’t thought of as ‘vascular’.

Well, that is debatable given the findings on SPECT imaging and the orthostatic symptoms which are so characteristic of ME.

People with ME often feel more ill when they are upright.

And standing still is worse than walking. We think this effect has a vascular origin.

Jane: Vascular means to do with blood vessels, doesn’t it?

Vance: Exactly. It means all blood vessels including veins and arteries and small vessels.

It is possible that the problems that ME patients have when they exercise might well be attributed to the blood supply to the muscles.

Jane: In what way?

Vance: It could happen directly or indirectly. For example, a clear relationship between musculo-skeletal symptoms and blood markers of oxidative stress in patients with CFS has recently been demonstrated.

We have also shown that specific markers of oxidative stress, isoprostanes, are increased in ME/CFS. This will be published shortly.

These isoprostanes are very vasoconstricting.

Jane: And the translated version?

Vance: [laughing] They constrict 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.

Jane: So as far as you're concerned, there could be a real problem with the blood vessels.

Vance: Yes, there could be, especially during exercise.

Jane: What would the consequences of that be?

Vance: We have evidence that patients with ME/CFS have a significant cardiovascular risk. Of course, it is difficult for such patients to exercise and this makes the risk higher. It's important to try and find out if that risk starts in children. We have *no data* on children, which is terrible – that is why we have to do this research.

Jane: That's what medical research should be about, isn't it? Searching for new information that might enable something to be done.

Vance: Yes it is. We have no idea whether the findings we have in adults will apply to children but, if we do find similar patterns, then we should be able to take steps to reduce risks especially in those

where the illness is chronic.

It's an exploration – but an exciting one. Our department already carries out substantial research on children, looking at early cardiovascular risk in those with diabetes and obesity. The ME/CFS research in children is a new direction for all of us.

Jane: What you've described isn't the cause of ME itself, is it? It's more the result of something that has happened to the body to make it go wrong.

Vance: That's right. And this research project will be investigating many factors, such as the response of blood vessels to nitric oxide and acetylcholine, and also apoptosis (cell death) of white blood cells, plus markers of inflammation.

Damage may have resulted from some kind of attack, possibly by a virus, and that effect may not have gone away.

Jane: Can psychological therapies have an effect on this?

Vance: They certainly can't make the problem go away, no!! They are designed to help people 'cope' with illness, not discover the cause of it. For that, we need proper biomedical research.

Jane: Quite.

South Australian Government publishes ME/CFS guidelines for GPs



Government
of South Australia

Choosing the 'opathy' ending (myalgic encephalopathy, rather than myalgic encephalomyelitis as used by the World Health Organisation) the Government of South Australia has published diagnostic and management guidance for GPs.

Using much from the Canadian diagnostic criteria – with a useful tick box to aid the process – this document also incorporates the David Bell CFS Disability Scale. Summaries of aetiology etc. are generally helpful.

The Australian guidelines have 'been developed, where possible, by achieving consensus between practising clinicians' and are intended for clinical use (as opposed to research).

Chapter 5 of the 2002 Report by the UK Chief Medical Officer's Working Group on CFS/ME – which The Young ME Sufferers Trust helped to write – recommended that ME in children be diagnosed in 3 months. The Australian guidance sticks to the more traditional 6 months – but no consensus document will please all. The British RCPCH guideline recommends diagnosis 'as soon as possible'.

However, the Australian guidelines are succinct, easily understood, useful, practical for a GP and, in our opinion, more helpful than the RCPCH guideline in several areas. It does not give detailed advice on education, but what there is, is good.

You can download Dr Alan Franklin's excellent guidance for paediatricians at www.tymestrust.org

Pushing the Boundaries in ME/CFS

In *Special Children Magazine* Jane Colby asks:

What is really going wrong in ME/CFS? New research may help to provide answers

Peter Ustinov once said, ‘We are united by our doubts and divided by our convictions.’ When it comes to the best way to treat and educate children with ME, that is certainly true. Disagreements over school attendance, curriculum, special educational needs, medical needs, school examinations, home tuition, virtual education, all arise because of conflict between strongly held beliefs among professionals.

Now the first ever biomedical study in children with ME, also called Chronic Fatigue Syndrome, has been announced by The Young ME Sufferers Trust. The Trust has co-funded the study with the research group MERGE and a contribution from a Scottish charity, Search ME.

Using sophisticated vascular imaging techniques, previous work by the researchers has already shown biochemical abnormalities in the circulation of adult ME patients, suggesting that ME could involve a continuing challenge to the immune system, such as a persistent viral infection.

The aim of the new study is to investigate a group of children with well-defined ME/CFS (in whom there is the possibility of long-lasting chronic ill-health) to see, for the first time, if similar biochemical abnormalities exist. If they do, children with ME/CFS may have a chronic inflammatory disorder associated with increased risk factors for cardiovascular disease, but encouragingly, the findings might become the basis for future treatment interventions.

Doubts are more important than convictions, and science needs to ask questions. Too little biomedical research into ME has been done, too little confirmed about biological mechanisms involved, and about potential treatments and harm to the body when the illness is badly managed.

With doctors arguing about medical management, how can teachers decide what’s best for their pupil? Teachers need to go back to the source – the children themselves – to devise a way out of this dilemma. We expect children to learn, so we too must be open to learning, not only from families about what, in their experience, is safe for their child to do without threatening relapse, but also from the latest research

showing physical damage, potentially from viral causes.

Gene abnormalities, cell death abnormalities, brain function abnormalities, muscle metabolism abnormalities, spinal fluid abnormalities – serious physical dysfunctions are being uncovered. They receive little publicity in the general media.

Unfortunately, myths die hard. Some seem to have a life of their own and rule everything we do: ‘The Myth is dead; long live the Myth.’ What is the main myth about ME? Surely, it is that ME is mainly psychological, or that even if it isn’t, psychological therapies will enable normal function to return in a few months or a year, enabling children to participate in school as they did before they were ill.

That path is fraught with bear-traps. It has resulted in parent-teacher wars with the child caught in the middle, tribunals, suspicions of child neglect or abuse, and even the threat of court cases where the duty of care is breached and illness is exacerbated.

[...]

Without a diagnosis at all, schools have difficulty in making special provision. Such is the concern over delays in diagnosis, during which deterioration can take place, that 2005 also sees another collaboration. The ME Alliance is a group of six charities, members of the Chief Medical Officer’s Working Group on CFS/ME, who all contributed individually to the 2002 Department of Health Report. That report decisively recommended flexible education for these children. The Alliance is now planning its first joint campaign on early diagnosis, with its own report for doctors.

Teachers cannot make medical diagnoses but, as I wrote in the first *ME Guidelines for Schools* in 1991,

it is not unknown for an alert teacher, seeing the child daily, to spot a pattern that could turn out to be ME/CFS. If a GP requests home tuition or other special arrangements, schools and LEAs should take serious note. No matter how desirable it is to obtain a consultant's diagnosis and recommendation, statutory guidance from the DfES in *Access to Education for Children and Young People with Medical Needs* states that sick children who have to miss school for over three weeks should have other provision made.

The *knowledge* boundaries in ME are starting to be pushed back, but we have a long way to go before there is full understanding and an effective treatment. In the meantime, unrealistic expectations, pushing too hard at the boundaries of *recovery*, is unwise and a more realistic approach is necessary. Dr Darrel Ho-Yen, a well-known medical author, microbiologist and ME specialist, has pointed out that in this illness it is by *living within the boundaries* that the boundaries expand as the body heals. A fair parallel is the child who can reach further the higher he grows. Growth has to come first.

Whilst relieving psychological distress is good and encouragement is also good, an educationist's true job is to find a way – not from previously held conviction but from open-minded and careful experiment – to help each one of our children achieve, and enjoy that achievement, in whatever way works best for them.

Jane Colby is a former head teacher. She is Executive Director of The Young ME Sufferers Trust, which is a member of the ME Alliance.

Tel: 01245 401080
www.tymestrust.org

The full feature can be read in Special Children Magazine, a publication for education professionals from Questions Publishing: 0121 666 7878 Why not get a copy for your teacher?

ON HOLD

Young Hearts Review
Reprinted with kind permission of Special Children Magazine (March/April 2005)

The cure you would like to have is currently unavailable. Please try again later.

The life you are trying to reach knows you are waiting. Please hold.

Your hopes are important to us – we will be with you shortly. Please hang on.

Victoria Flute

From *Young Hearts*

A poetry book is rarely a page-turner. This is the exception. 'I honestly could not put it down,' comments an educational psychologist who sees children with ME regularly. 'I feel I am really starting to understand what it must be like.'

This remarkable poetry collection by over 40 children and young people with ME has been launched by Terry Waite CBE, former Special Envoy to the Archbishop of Canterbury and middle-east hostage.

Jade Louise Scarrott was fourteen when a random road accident cut short her life. She had suffered with ME for four years. Her poems are published in *Young Hearts* along with contributions from children and young people aged seven to twenty-six. Jade conceived the project and its title to raise awareness; the shock of her death determined everyone involved to dedicate it to her memory.

Some of the poems are cries from the heart: '*I'm no different to anyone else. I'm just ill.*' Some are funny (*The Spider in My Room*), some contemplative (*Snow Falling*). Not all are about illness. What they share is the ability to touch us and leave us different from before.

Children with ME can become isolated, lonely and forgotten: '*I am the child who disappeared, passing like a shadow from your lives...*'. Despite such privations, the amazing spirit of these young people shines through their words. As Terry Waite says in his Foreword, 'Suffering need not destroy.'

My world's stopped, but life goes on -

And I've time to drink in each new dawn.

Young Hearts is perfect for young people with ME, families, friends and schools. It is available for £7.95 (inc. P&P) from The Young ME Sufferers Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE. Tel: 01245 401080. You will find an order form at www.tymestrust.org

You Tell Us

Elizabeth's story...by her mother

We are struggling our way through this GCSE year. I have given up work to help Elizabeth through it. Her school have at last accepted that she really is ill.

At the sixth form open evening I was the only parent there without their child, because she was ill in bed. It hit me hard how different she is to everyone else in her year.

She has been given a lovely school report. I have told them that all I want from them is to be kind to her between now and June, and that they will not gain anything by putting pressure on her, and I think that they are listening. She has commented that during the little time she spends at school all the teachers have been talking to her.

One of her teachers found a creative solution for GCSE Maths – International GCSE Maths, which is sat in May and has no coursework. It's a different syllabus but it means she can get that subject out of the way and has one less to worry about during June.

The school have also been supportive about A levels. Elizabeth will continue at school (which is only five minutes walk) for A level French and will use the Nisai virtual classroom* to work from home for two other subjects. She is looking forward to this and I am hoping it will prove to be a better way of learning for her.

I was working up to writing to the headmaster about her plans, when he phoned me to ask how she was. When I explained what she wanted to do he was totally supportive and said that he agrees we need to make sure she does not have another relapse.

This was a great help and I arranged to see him the next day. I gave him a copy of *Young Hearts* and asked him to put it in the school library.

I also mentioned it was her birthday. I talked about the new group of friends she has made and that her teachers may see her out with them when she has not been at school, but that I support her in this as she needs to have interaction with young people.



Elizabeth Colley

Elizabeth had a better birthday than she has had in years. Most of it was spent quietly revising French but from 4pm she had a string of visitors - mainly male! She rounded this off with her favourite meal. Although it was a simple day she was thrilled that so many people called to see her.

I think more than anything it brought home to me the isolation that her ME has caused and the loneliness she has faced for a very long time. Over the years one by one her friends have dropped away and lost interest in her. I have felt powerless to do anything about this and deep down have been terribly hurt and upset for her. I think that the *Young Hearts* poems help to convey some of this pain.

I am very proud that at last she has made new friends who can accept her for who she is. They don't mind if they don't see her for weeks and don't expect anything from her. I can tell she is much happier and feels much less cut off. We seem to be getting quite a few visitors calling round to see if 'Liz' is in - a bit of a joke for someone who scarcely goes out! However, it is great for her confidence and I believe she will be much happier for it.

It has been wonderful to see a smiling Elizabeth again with bright, sparkling eyes. She has had another bit of a downturn recently – but that's life with ME!

Many thanks to you for everything that you do for Elizabeth and all those like her. It makes a big difference to her and to me.

Jane Colley

PS

I hope you will be pleased to know that John Clare in today's *Saturday Telegraph* mentions Tymes Trust. A few weeks ago he mentioned Internet sites. I e-mailed him and said that in circumstances like Elizabeth's these sites do have benefit, as writing coursework without attending the relevant lessons is rather a nightmare!

I talked about the difficulties of doing exams when you can't get to school and said how much help we had received from you. I explained that next year she will be using Nisai for two A levels, and he has referred to them as well. I am emailing him back thanking him for mentioning Tymes Trust and Nisai Education.

* *The Tymes Trust/Nisai Education Partnership provides a Virtual Classroom. If you would like details, ring our Advice Line on 01245 401080*



Dear all at TYMES

I am an 'honorary' member of your fabulous magazine and read with interest that you were asking anyone who had been to university or college to share their experiences with other young ME sufferers. I have a wealth of good and bad experiences and tips to share.

I have been ill with ME for 21 years (since the age of 9) and my education has been somewhat truncated with an 8 year sabbatical during which time I was paralysed and bedbound and in hospital for a year, but all is well now after a few hitches along the way.

With best personal wishes, and continued success in producing such a fabulous and inspiring publication.

Sarah Stokes

NEW – E-PALS!

If you're feeling a bit out of things, you could try our new E-Pals scheme. Just go to www.tymestrust.org and use the Contact Form. Write an e-letter about yourself and we will forward it to your new E-Pal.



Hidden

I breathe;
but i don't live.
I watch;
but i don't join in.
In dreams i live and i am free,
awake, i am in prison.
My past;
I'm free.
My present;
I'm caught and chained.
My future
Is hidden.

Charlotte Bibby



Wishes

To be free
is a great wish.
To live and feel alive
is an even greater wish.
We all wish
to be taken from the dark,
to be brought to the light,
to be accepted again;
I wish.

Charlotte Bibby

'It is easy to feel that the treatment you're being offered is the only thing that might help you. It was good to be reminded that there is not a straight cure as it is easy to forget that. That knowledge makes the decisions I make easier.' *Efchi*

SEB'S MANOR



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



Thank you for the lovely hanging bears you sent Kat and myself. Mine is hanging up over my bed (and was included in photographs taken for an article for Readers Digest, so he's maybe in there!) and Kat's hangs off her IV pole. Kat is finally home after 6 and a half months in hospital, but is still reliant on IV's and has nurses coming in and out.
Vikki George



I am looking after my sparkle bear, it was a lovely surprise to get her. I am going to take her on holiday to Switzerland with me. I won't be able to do much but I am sure to have fun. My teacher is Mrs Kydd. She is so kind and helpful to me and I really would love her to get an award. I am going to have a rest now before we have to leave for my holiday.
Love from
Michelle Cross

Sebastian says: I have honoured Mrs Kydd with my Order of the Golden Web. If you would like one for your teacher, send her name to us and please send a donation to cover the cost. Michelle also came to the special Young Hearts Day held at Stock Tea Rooms in Essex.

Sebastian says:

I can hardly bear (ouch!) seeing our tiny sparkle bears go venturing out into the Wide World (even in padded bags) but it seems you're taking proper care of them and even taking some of them on adventures. There are a few still waiting for good homes – would you like one? Just write in and tell us where they will hang out if we choose you!

Thank you very much for our letter writing prize, Fudge and I will enjoy reading the book we choose with the Voucher, we are saving our voucher as we would like to buy the new Harry Potter book when it is released, although Fudge cuddles Max* when I read the scary bits.

The prize arrived just after I had recovered from Flu so it was a lovely surprise. Fudge and I opened it together. We love the address book as we love things that glitter. We also enjoyed reading the *Vision* magazine but missed Trusty. Is he coming back?

Love

Cheryll, Fudge and Max

*Other Christmas Bears!

Sebastian says: Trusty has been hibernating. He is the only hibernating dog in the world. He woke up in January and has been running all over the place ever since.



Dear Jane and staff
at Tymes Trust

Thank you for my birthday and Christmas card you sent to me. I liked them a lot. So I have sent you a Christmas card.

from
Jodie Halliday

TRUSTY SAYS : 'WOOF! Amazon.co.uk/WOOF!'

We think he means, 'Don't forget to do the same as Sazza! It doesn't cost any more to buy your stuff this way and only takes a jiffy!'

So go to www.tymestrust.org first and then click on the link to Amazon. It really helps our funds.

You can make a difference just by buying stuff you were going to buy anyway!

There are no extra forms to fill in.

All monies go to services for children and young people with ME.



'Do I have to wake up?'

Email:

I'm writing to say a REALLY BIG THANK YOU for my prize in the Shirley Conran letter writing competition. Having had to drop one of my two A/S Levels for the 3rd time, I was feeling very frustrated. It was a big boost to my self-esteem to receive it. I won't forget that moment!

The address book is beautiful and I'm going to purchase a self-help book of some kind (via your website's Amazon link of course!) with the vouchers.

Sazza Holmes



SEB'S TREASURE CHEST

Would you like some of my treasure?

I've got all sorts of things in my treasure chest – I've been collecting for ages and it's got so full I'm having a special Treasure Give-away. Some of my stuff is from the House of Lords even!

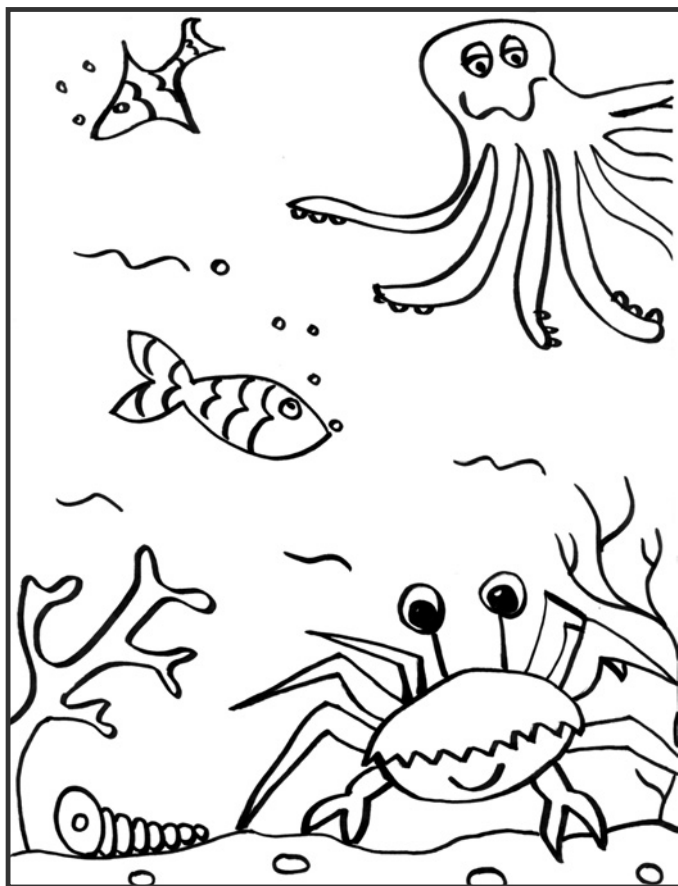
The good news? You don't have to enter a competition to get a gift from the Treasure Chest – all you have to do is send me something I like for my page!

It could be a drawing or a poem – or a card telling me how cool I am...

It could be a photo of you. Whatever. I'm waiting.....



Colour Me In by Laura Shave



Young Hearts Inspires More Poetry

Katie Evans, contributor to *Young Hearts*, was inspired by the book and by her experience of 'fair-weather friends' to write more poetry.

SO THERE!!

My friends said that they'd always care
My friends always said that they'd be there
But after a year they all just forgot
they didn't know where? why? or what?
The ME - the illness that I got
Freedom, strength it took the lot
From light to dark after a year
I asked for their help but they didn't hear

The longer the days the lonelier nights
I won't give in I'll put up a fight
So I made some new friends
who know and who care
We all have ME and all learnt to share
The sadness the courage we all had inside
We put it together and made it all rhyme
In the poems the stories that we all wrote
In them the sadness love fear and hope

We don't get to run we don't get to play
We sit at the window day after day
Hearing our friends all having fun
Running around playing in the sun
Years ago that would have been us
Playing with friends and making a fuss
But staying inside and watching, for now
always knowing who? what? and how?
This illness has given us one thing for sure
It's given us a thirst for more and more
To get better and – well – to show them all up
Knowing one day they'll be out of luck
The days that we're well and going about
Catching up on the fun that we missed out.

Katie Evans



A Letter from.....Shannen Dabson

I'm Shannen and I've just turned 10. I've been ill for 18 months and I'm finding more and more things to keep me cheerful. I'm able to do more than I could a year ago but I haven't enjoyed going to the hospital as I hate needles and trudging from one appointment to the next.

My friends have been fab. I'm part of a Sleepover Club although we've only had one sleepover. I've joined the Guides who were very understanding and of course there's my pen pal Dawn. Hi, Dawn! I have lots of cuddly toys as I want a dog but can't manage one yet.

I get a lot of visitors as I'm not the only one in the family with ME. I'm able to do something most days, even if it's just Mum painting my nails or getting the paints out for me. The biggest joy I've discovered is the local library. I've ordered lots of books on Spoken Word from the Famous Five and Black Beauty to The Giggler Treatment. I'm now mad on Lemony Snicket and I saw the film for my birthday.

My bedroom is just how I like it as I spend a lot of time inside still. I have my certificates and Blue Peter badges by the side of my bed from whenever I do something cool or have an idea for the show – they must be fed up with me writing!

My latest thing is to sit in a huge box (from our new TV) and think of inventions. I like to sit there because it's dark and cosy and I've decorated it. Mum calls me Violet because of the girl in 'A series of unfortunate events'.

I don't go to school much, as they've yet to sort themselves out or get me any tutors. However, my friends write and text me. I have bugs on the bunk above me and I stretch my legs up to them for exercise. I hate the way ME makes my hair and eyes go when I have a 'mouldy' spell.

I love having my legs massaged with 'tired leg gel' and I love receiving letters.

I go in for lots of competitions and make woollen balls, cards and create lots of art. If you're going to feel yucky it's nice to have a beautiful picture to look at or a cuddle from your pet.

I love baths but the hospital has told me to cut down!!! Now you understand why I don't like hospitals. The bath is the only place I always feel better.

Love to all the readers.

Shannen

Why not write us a letter? Or write to Shannen c/o The Young ME Sufferers Trust

Dr Betty Dowsett says: 'It is the temperature of the bath that is important – it should not be too hot, to avoid a risk of relapse. People with ME have impaired body temperature regulation and getting overheated can interfere with the functioning of the nerves.'



Terry Waite launches *Young Hearts at Warwick Castle*

The Courier/Weekly News
The Observer Series

Terry pays tribute as Jade book launched

Hundreds attend ME poetry book launch

Fragic Jade's wish becomes a reality

Moving poetry

Poetry book is tribute to Jade

Remembering Jade

Jade's insight lives on through poetry

New book sees dream realised

Book a fitting tribute to a very special girl

Warwick Gazette
Evening Telegraph

Jade's Dream Appeal

Karen Scarrott has now let us have lots of beautiful key-rings and badges that you can buy to show support for Jade's dream – to raise awareness of children with ME. All funds raised go to Jade's Dream Appeal.

Keyrings and badges cost £1.50 each including postage and packing. Send your cheque to The Young ME Sufferers Trust, PO Box 4347, Stock, Ingatestone, Essex, CM4 9TE.



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