

The Young ME Sufferers Trust

2008-2

£3-95

Vision

for young people, families and professionals

YOUNG HEARTS DAY 2008

Edinburgh remembers children with ME

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Free monthly news from the Trust

ENTEROVIRUS PROJECT

Trust works with John Chia MD

THE INTERVIEW

Nasim Marie Jafry

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Oxygen Deprivation During Exercise

Explain Your Abilities: get our self-help tool

ME? It's Kids' Stuff : Virus spreads in schools

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THE YOUNG ME SUFFERERS TRUST

Registered Charity Number 1080985

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Our Patrons



Lord Clement-
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Earl Howe



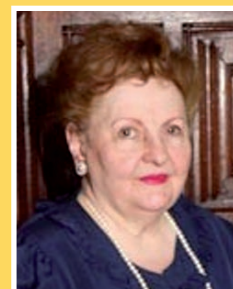
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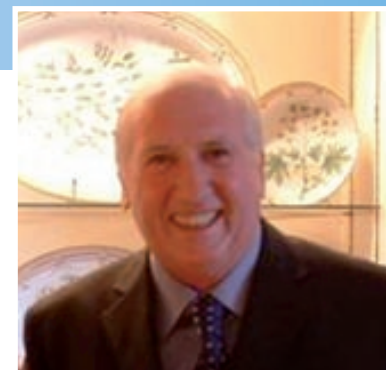


Terry Waite
CBE



Barbara Windsor
MBE

Vision - The Project



Keith Harley

local paper each week and send us any ME stories you find? Working together makes the Trust what it is.

So come and be part of it all! My very best wishes to everyone.

Keith Harley
Chair of Trustees

Welcome to all our new readers and greetings to our regulars. By now many of you will know that we have moved into a new phase of the Vision project.

This year we decided on a new way of keeping you up to date with the Trust's work, whilst also using our resources wisely; these resources are made up of donations that you and those like you have given and we know that you want them respected and carefully managed.

So we've turned to the internet once again. In common with most young people, we regard the internet as an ally. Like all media, it can be misused, so young people do have to be careful and parents need to keep a watchful eye, but it is of course a modern and powerful tool. The Trust wants to employ it to help us keep in contact with you more frequently, in a cost-efficient way.

Free Alerts Club

To celebrate our birthday this year, Mark Colby set up our new Alerts system. My thanks to those who made initial donations as we trialled the service. We received excellent feedback and so now we've set up an Alerts Club with free membership. Why not join today?

Alerts will come to you once a month on average - which means that some months you won't get one at all, and then, like buses, three may come along at once! On page 14 you'll see news from some of the Alerts that have gone out already. There will be more soon.

To join the Alerts Club, go to www.tymestrust.org and enter your email address in the box at the top, or email us using the Contacts Form on the website. Say that you want to join our Alerts Club. It's totally

confidential and safe and you won't be sent any junk mail.

Alternatively, you can telephone our Advice Line Team, but be careful to dictate your email address accurately!

If you're in our Alerts Club you'll know as soon as anything new goes online on our website, which brings me to my next announcement.

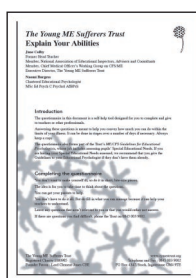
The Brief by Jane Colby



The latest issue of *The Brief*, which you'll find in this issue of *Vision*, was uploaded to our website for you at the end of September, as

those in our Alerts Club will know. This is part of a rescheduling of our publications. We shall now publish issues of *The Brief* on our website in between issues of *Vision*, giving you something new twice as often. Of course, you'll get your printed copy with *Vision* as usual.

Explain Your Abilities



We also have another new publication, discussed on page iii of *The Brief*. It's a self-help tool to enable young people and their

parents to inform their teachers and others about how much they can manage without becoming unwell, and about their general needs. Like *The Brief*, it was uploaded to our website at the end of September and those in our Alerts Club will have received the news in early October.

Finally, we're looking for people to join the Trust's Team as press-spotters - could you check your

Judicial Review

Jane Colby has provided the Trust's evidence supporting Kevin Short and Doug Fraser's case in the Judicial Review they have achieved through Legal Aid of the 2007 NICE Guideline on CFS/ME. The Court dates are in February; we hope to be attending the hearing.

Forward-ME

The Countess of Mar invited the Trust to take part in the new Forward-ME forum which she chairs; to date there have been two meetings in the Palace of Westminster. We are always happy to talk with other groups and take part in joint projects where appropriate. The Trust's position is that ME should be separated from CFS in guidance. We still consider it to be essentially an enteroviral illness, although there are many factors in any illness compounding the effects of the infecting agent. These factors affect host response and can include other infections or traumatic incidents. Symptoms caused by the enterovirus may be minimal in the beginning, with the complications following on.

Young Hearts Day

29 November 2008 - remembering young people with ME



www.youtube.com/watch?v=ga3BphlnA-E

Young Hearts Poetry video

We thank Creative Director Lesley Scott, Editor/Director Peter Scott, School Co-ordinator Mrs Lesley Kelly, Drama Co-Ordinator Mrs McDonald and the 3rd Year Drama Department of the Community School of Auchterarder for their work in creating this wonderful piece of art for Young Hearts Day 2008.

Narrators: Claire Balingham, Katie Langlands, Rhona McNicol, Claire Mercer, Richard Holt, Lesley Scott, David Scott, Mrs Samantha Holt.

Poems on the *Young Hearts* video:

- Different* by Ana-Alicia Bryant
- My Window* by Rachel Gooden
- My Hell* by Rachael Marshall
- Tears* by Sheena Hewitt
- On Hold* by Victoria Flute
- Heather* by Linda McLean
- I Feel* by Helen Davies
- Hanging Out In Bed* by Robin Sansom
- You Don't Understand* by Heather McLean



Lesley and Peter Scott

What a great project! This YouTube video of *Young Hearts* poetry was made by Peter and Lesley Scott and the students from The Community School of Auchterarder. To say it is 'moving' sounds as if it is purely emotional rather than giving a potent and informative message, which it most certainly does.

Peter's brother has ME and knows what it's like. If you can watch this video yourself and persuade others to watch it too, I would really recommend

that you do, because it will advocate for you. Who

could remain unaffected? The spirit of young people with ME as expressed in the poems conveys the stark reality with a total lack of self-pity. And the way these young Scottish students interpret the poems afresh is to be commended.

The music adds to the experience and the clever imagery creates an amazing atmosphere. Those who took part in this project should be justly proud of their achievement and to everyone reading this who is struggling with ME or caring for someone who is, I send my thoughts at this special time of the year.

Lord Clement-Jones CBE
Founder Patron

Young Hearts the book is £7.95 including post and packing. You can send a cheque or use the Donations form at www.tymestrust.org giving the order information in the message box. Launching the book in Warwick Castle 2004, Terry Waite told us: 'Suffering need not destroy. Something creative can come from the deepest grief'.

Read about poet Rachael Marshall on page 22.



with the writing awards regular readers will know. Some of you

This autumn we began helping Shirley Conran with a special project that has nothing to do with the writing awards regular readers will know. Some of you are already taking part. We can't give details publicly yet because of confidentiality clauses, but if you'd be interested and are 14 or over, we may well be able to include you.

Talk it over with us on 0845 003 9002.

This was a complete surprise. I could watch it over and over. I probably will! I've read the poems often - I edited the book after all - yet they never fail to move. These students, parents

and teachers have brought the words to life in a new and amazing way. Every school should watch it. Thank you, all of you who put it together.

Jane Colby

Our Welsh connections remain strong. Chair of Trustees Keith Harley and Executive Director Jane Colby were the guests at the Clwyd ME Group's Annual Conference, a Partner Group to the Trust. Jane quoted a personal email from virologist John Chia, with whom the Trust



Annual gathering helps to raise ME awareness

EXPERTS from across the country came to share views at ME (Myalgic Encephalomyelitis) Clwyd's conference. The annual event, held at Connaught Civic Hall, took place last Friday. ME Clwyd provides support to people in the county suffering from the debilitating condition. Speaker Jane Colby from trustees, the chief executive of The Young ME Sufferers Trust, told the conference of the latest research findings. She revealed US virologist Dr John Chia has linked ME to enteroviruses and polio and is researching the use of antiviral drugs to treat the condition. "ME is an old but newly characterised viral infection which affects more people in the UK and US than hepatitis and AIDS," she said. Clinical dietitian Penny Cowley, who also speaks at the conference, said: "Many special diets claiming to help people with ME lack any evidence to back them up. Weight change can be a sign of concern for people with ME. A reduction in physical activity associated from lethargy caused by the illness can lead to weight gain. Similarly, nausea caused by ME can lead to weight gain. "It's important to keep your energy topped up throughout the day to avoid boom and bust levels." Event organiser Barbara Turnbull, the group leader of ME Clwyd, was diagnosed with the condition 20 years ago. She said: "I was devastated when I got ME. It began as just a bit of cough at the back of my throat. I was always so busy but ended up not



TALK SHOP: Speaker Penny Cowley, speaker and Young ME Sufferers Trust executive director Jane Colby, Mark Tami MP, Young ME Sufferers Trust trustees chairman Keith Harley, ME Clwyd group leader Barbara Turnbull and Jane Harris from the Morgan Foundation at the ME Clwyd conference. VF16568CONF

is working: 'ME is an old but newly characterised viral infection affecting more people in the UK and US than hepatitis and AIDS.'

Jane Colby, Mark Tami MP, Keith Harley and Group Leader Barbara Turnbull with other guests.

Thanks to everyone who completed a questionnaire for *The Colby Report* during 2008. All who expressed interest in this project will hear from Jane personally.

In The Spotlight it's the law, stupid!

Do you remember that phrase 'It's the economy, stupid!' that President Clinton's team used to help unseat the first President Bush?

In the context of ME, it's the law - children's rights, to be exact - that can be used to overcome injustices that children with ME are facing. It's not easy and it can be exhausting but if Local Education Authorities and others are not challenged over the legality of what they are enforcing on children with ME, these injustices will persist.

In the November 2008 issue of the MEA magazine *ME Essential*, I describe how education is a central problem because 'education services often neglect the legal rights of children to suitable education under the law and this not only means they can't achieve success (a desperately dispiriting thing in itself) but it undermines recovery and causes repeated relapse.'

I also point out that:

an audit of our Advice Line showed that 90% of calls concerned education, or education was part of the problem in our 2004 survey, 81% of the families had changed schools to get their children's needs recognised - a huge percentage given that people don't change

schools at the drop of a hat - it's a big thing to undertake; education professionals are often involved in referrals to social services because they can't believe there's a good reason for the child not to be in school - even after a consultant or a GP has told them there is.

I recently addressed the All Party Parliamentary ME Group about erroneous referrals for child abuse or neglect. If it's not that, it's threats of prosecution for 'truancy'; one parent was recently fined a substantial amount.

The situation isn't helped by some paediatricians who use school attendance as a kind of graded activity programme. When teachers feel they have to go along with this nonsense, they need to know that merely using attendance to measure success can not only contravene the child's statutory educational rights but it can also contravene the Disability Discrimination Act.

Schools are there to promote learning. If bums on seats were the measure of success, there would be no need for GCSEs, A-Levels or Diplomas, and the rest. The child would only need an Attendance Register to show potential employers.

As a former Head Teacher, I'm unhappy that my own profession is widely guilty of injustice to children with ME. Our 2004 survey showed that 84% of children felt bullied by education and other professionals; their illness often worsened due to unsuitable - and often illegal - demands.

As our Welfare Rights Adviser recalls, her own Local Education Authority had to 'admit to serious shortcomings in provision of education for my ill child'; they 'wrote to the Local Government Ombudsman to say they'd offer £3040'.

I would be the last to advocate conflict where common sense and reasonable discussion can sort things out - we specialise in helping with that. But where these don't work, schools must realise: it's the law.

Excerpts taken from 'It's the Law, Stupid: Jane Colby believes that when children's rights are ignored, it's time to get tough' in ME Essential, Issue No 108, November 2008, ME Association.

CHILDREN
It's the Law, Stupid!
JANE COLBY believes that when children's rights are ignored, it's time to get tough. **It's the Law, Stupid!** is a collection of articles from the Young ME Sufferers Trust's newsletter, *ME Essential*, which are available to read online at www.meassociation.org.uk. The articles are written by Jane Colby, Executive Director of the Trust, and other members of the Young ME Sufferers Trust. The articles are written in a straightforward, accessible style and are aimed at parents, carers and professionals who are involved in the care of children with ME. The articles cover a range of topics, including the legal rights of children with ME, the impact of ME on children's lives, and the role of schools and other professionals in supporting children with ME. The articles are written in a straightforward, accessible style and are aimed at parents, carers and professionals who are involved in the care of children with ME. The articles cover a range of topics, including the legal rights of children with ME, the impact of ME on children's lives, and the role of schools and other professionals in supporting children with ME.

what you think



As a young person, currently wheelchair-bound with ME, and a member of the Tymes Trust, I have very strong feelings regarding the need for government funding for biomedical research into the condition. I have been inspired by the Tymes Trust publications. I had originally hoped to write an article to send to the press for ME Awareness Week but the writing took longer than expected.

Excerpt: A number of patient groups, including The Young ME Sufferers Trust and the 25% ME Group, advocate the separation of ME (which is thought to be a neurological illness) and CFS (which is believed to be a collection of symptoms too imprecise for a distinct diagnosis).

Naomi Hooke

Naomi mentions that the World Health Organisation (WHO) lists ME as a neurological

condition (see back page) but those writing the NICE [National Institute for Clinical Excellence] guideline were split over whether to include this. They finally omitted it.

From the beginning, the Trust argued for ME and CFS to be separated by NICE. Jane Colby has provided a Witness Statement supporting the Judicial Review of the NICE Guideline, which will take place in February.

I have been receiving *Vision* for many years now. Have found it very helpful. I have suffered from ME since the age of 14. I am now 22 yrs old and my health has improved greatly - am hoping to go to university to study nutrition and dietetics, something I never thought would be possible. I feel my free copy of *Vision* should go to someone who needs it more than I do so very many thanks for all your good tips in *Vision*. There is a light at the end of the tunnel for ME sufferers out there.

Sarah Colson

If, like Sarah, you don't really need Vision any more, but would like to continue to get it (for information or interest, or just to support the Trust) you are welcome to subscribe for £10 a year, just like the members of 26+.

Many thanks for Edward's birthday card. He has few friends being at home and it was a nice surprise to receive an

extra one. He has passed his Grade 8 singing exam with Distinction! We are so pleased and proud, it was worth the effort. He took

Dear Friends,

Emails are so much easier than cards! The attached picture is from my retreat in September and comes with my love and



best wishes for a happy and peaceful Christmas.

Zoe xx

Voicemail Messages

'It's Sharon Cox here, I'm ringing on behalf of my daughter. I just wondered if you could pass the message on to Jane that we're absolutely delighted with the Nisai Virtual learning, Chloe absolutely loves it. She's really really enjoying it. I would highly recommend it to anybody.'

'Hallo, this is Fay's mum ringing up to thank you for the help and support that we've received since she was diagnosed at the age of 12. She's now 26 today. Your cards for birthdays and Christmas have been absolutely amazing. I can't thank you enough for the support. We will be joining 26+ for the year because we don't want to lose contact with you and I will also get a selection of birthday cards sent on to you as well in thanks for all the support you've given us. Thank you very very much.'

Why not leave us a message on our voicemail? Tel: 0845 003 9002



I often get asked 'how do I cope so well with my illness'? Don't I get angry, sad, bored even? And I don't, at least, not any more.

Sometimes I still get a little frustrated when I can't do what my friends do - but I've accepted it. It's like winter following autumn. It is no surprise and it's also no surprise when I'm ill for more than six months of the year.

It does make life more difficult and I feel sad when everyone else is having fun, snowball fights and Christmas shopping when the closest I'm going to get to those things is watching them on TV. Sometimes, to feel better, I think of it as going into hibernation like a hedgehog or tortoise!

After 5 years of ME, to not accept it would be like denying winter was coming and wearing my summer clothes in November! Sure I like my shorts, tanned skin and shiny hair more than my jumpers,

The good news is that Peter is now 24, and moved into his own accommodation about 18 months ago. He has made a remarkably good recovery over the years, and is very physically and mentally fit these days. Just occasionally



chapped lips and rough skin but no matter how much I like the summer I'm not going out in my shorts in

December for anyone. Likewise I'm not going to act as if I'm 'normal' when I'm not. I'm not going to get down in the dumps when the first signs of a relapse occur because it's the same as winter coming.

Instead, I prepare for my 'bad spell'. I do activities in the summer so I have pictures and memories for 'winter'. I find book signings, events, plan fun days out with friends. This 'winter' when you are ill in bed, try

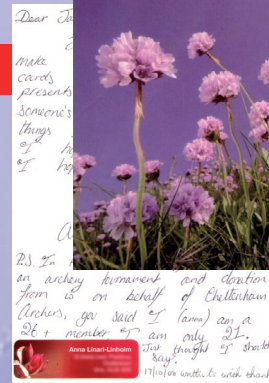
planning fun activities for your next summer. Get someone to write down your ideas. Also, when you go places, take your camera. Take pictures of everything and everyone. Those smiling faces and happy memories will get you through

Shannen Dabson, 14
Tymes Trust Young Advocate

I see the twinges of tiredness from the past, but he is well able to manage this himself. I do want to say how much your vital service has helped us over the years, and I have been so grateful for all your help, advice and information in the past

when Peter was at his worst. Thank you so much, it was indeed wonderful that you were there. May God continue to bless the service you provide.

With my very best wishes
Angie (Pete's Mum)



Just wondered if you could make use of these

birthday cards and other bits as presents or prizes to brighten up someone's day. I know that the things I've received have really helped.

With kindest wishes, Anna and Pam Linari-Linholm

Thank you Anna for the lovely things - we will enjoy finding them homes! Anna is 21 and we said she was 26 last time. Sorry Anna!



I have registered my daughter as a member over the weekend. She suffers

from ME and we are really interested in the Trust Card. Would you be able to let us know how to register for one of these as we think it will really help her when she manages to go to school.

One of the hardest things I think for her when she goes to school is the extra worry of having to explain everything over and over again. I think this card is a brilliant idea!

Thank you
Alison

Let us know if you would like a Trustcard - a passcard to support you in school.

Whenever you write in or email us, don't forget to say if you'd like to be quoted in Vision. It means a lot to know what you have found helpful - and it also helps us to plan. Send us a photo as well if you can!

WHAT HAVE YOU BEEN DOING?

I have signed up for email Alerts from Tymes Trust. Here is a picture from my Book of Days - a two-volume book of 60 flower paintings each, with verses below, which I have painstakingly completed during the last few years of my illness, in the hope that one day it will help others with ME, and their friends and relatives. I am hoping to get it published within the next two years.

I have been reading online the older issues of your mag. I wish I had known of it much sooner, it is a real

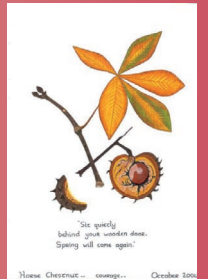
encouragement, even to adults, and I have been enjoying the articles so much. Thank you.

Brigid O'Connor, Minnesota

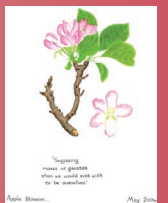
PS! The title of my forthcoming book is Blossoming Desert - A book of Days. The idea is to show that even the desert can bloom, beauty can spring forth from barrenness, hope springs eternal - and even at the most bleak moments, beauty is born. Courage!



I'm Still Standing!



"Sit quietly behind your wooden desk. Spring will come again!"



"Sipping from a garden after an arid day with the sunbeams!"

When our children are diagnosed with ME and often long before the diagnosis, as parents we feel a sense of desperation, isolation, helplessness and grief. When our son was diagnosed at the age of twelve, after eighteen months of illness, we found ourselves in turmoil not really knowing what to do for him or how to cope with his pain. The medical profession could offer no solution. We spent night after night trying to comfort a child in agony where no amount of medication gave relief. The everyday problems faced by our son and family were very different to those faced by adults with ME.



With the help of the Reading ME Support Group we began to make contact with other parents within Berkshire. What struck me most as an ex-community nurse when I began to talk to other parents was that we were all doing different things to achieve basic services for our children. There was no consistent protocol for the assessment, treatment, education and practical support for these children and their families. Some were struggling with severely disabled children without any advice from social services. On the 26th June 2008 a small group of six parents finally met for the first time. We exchanged stories, offered practical advice and reached out to one another with a level of understanding that no

professional, no matter how compassionate could offer us. We now have the beginnings of a network which we hope will enable us to help each other and our children.

We don't yet know where this group will take us or our children, but what we do know is that the face to face contact made a difference to us. If you would like to join us then please contact us through the Trust. If you are not in our area please think seriously about starting your own group. Anything that helps you as parents and carers has to help your children!

Brenda Dean

The Trust has Partner Groups around the UK. Would your local group like to be a Partner Group?

Helen Wood spoke to the *Western Daily Press*: 'Her exercise therapy involves her walking up and down the stairs or getting in and out of the bath.' We are not surprised to hear of Helen's trouble with her legs; we recommend pacing yourself, rather than exercise therapies, until you are greatly recovered. See our *Professional Guide Care of CFS/ME in*



Children at www.tymestrust.org by Dr Nigel Hunt. First published in *GP* magazine.



I wanted to say how much I've been enjoying the magazines, they are so full of great things and are lovely to receive.

Love, Claire Wade

Claire has put together a website with tips on living and coping with severe ME: www.survivingsevereme.com.

The feeling Better Rainbow

In a forest far away where the large oaks grow tall and the magic of the night lights the sky, a girl named Rhiane sat by her castle window.

She had not been feeling well for quite a while. She was a princess and daughter of a powerful and famous magician. She was under the magic cover, given down to her in the family. She was touching a flower that a fairy called Keira had picked for her.

All the other fairies were doing a dance around her, combing her red hair and blowing fairy dust onto it, while some others sat and watched. A bird of freedom was sitting and looking on at all this.

Two of the fairies, Lissy and Keira, talked together in a private fairy language that only they understood. Lissy came back and whispered to the princess, 'We can make you better.'

'How?' she said, in her strong Irish accent.

'By using the colours of the magic fairy rainbow we can use each colour for each worry and illness,' she continued.

Princess Rhiane knew it was totally beyond her knowledge. The fairies still danced till the last magic of dawn was lost. After the morning sun had risen, Princess Rhiane realised that she felt better, her pale skin was full of colour, her lips were rosy and she could bound out of bed doing the fairy dance.

'You are better'... 'you know you are'... 'and this is what the Rainbow colours do.' The fairies sang with music played on tiny fiddles and bodhran drums.

Katherine wins a Shirley Conran Writing Award and an art prize for her colouring. Tymes artist Susie has drawn you another picture to colour (page 12).



But what happened next, that Princess Rhiane couldn't see, was that she had been turned into a mischievous nymph.

Moral: Don't always trust the Good People.

Katherine Perry



I have some great news! I did an English home school course last year and did my language GCSE. I passed with an A! I also entered a poetry competition and my poem didn't win overall but it did make the finals and is to be published in a book called *Angels' Breath*. So, all *Vision* readers, you may feel that you can't do anything, but you can! You

really can! If I hadn't had ME then I wouldn't have found my talent in writing stories and drawing. So find something you're great at and develop your talent. I can't enter competitions to go to tropical islands or adventure holidays. I look at what I can do and do it. I hope you're all feeling as well as possible and you will beat ME.

Chloe Halstead

Find Chloe's artwork in Seb's Manor and her competitions in Things 4 U 2 Do.

I enclose a cheque for £50. We had a tea party recently, our neighbour Pam gave over her garden and she and my mum Lesley baked a mountain of cakes. Other friends helped including my friend Kat who also has ME. We were lucky to have a sunny day. Half of the money raised went to the Stables Family Home Trust - a local charity that help adults with learning difficulties. It was very rewarding

to be able to help other people too! As you know I'm off to Bristol Uni soon but I plan to stay in touch!

Best Wishes, Katy Brackston

Dear Jane and Tymes trust fund
I enclose a cheque for £50. We had a tea party recently, our neighbour Pam Pitman gave over her garden and she and my mum Lesley baked a mountain of Cakes. Other friends helped including my friend Katy who also has ME. We were lucky to



Meet The Team



Good Luck Katy

We say goodbye (for the moment!) to our youngest Advice Line Team member, Katy Brackston, and congratulate her on her success. She has been an asset to the Team.



Jennie Whitlock

is one of our Trustees, whom many of you will know from her personal notes.

Dear Chloe

You will be delighted to know that Seb has

Joy Birdsey is one of our newest Advice Line Team members. She runs KASAME, a Trust Partner Group covering Kent and Sussex. She is a tireless campaigner with a professional background and we are delighted to welcome her to the Team.



The interview went well yesterday, there was much interest about my involvement in the Tymes Trust and I've been offered a place to read Audiology starting at the end of September. Bristol University disability centre told me to be sure to tell people I have ME; apparently they have noticed how bad ME sufferers are at doing this, it certainly applies to me! Applying for DSA is worth it, I had a very empathetic and knowledgeable assessor and have now been given quite a bit of useful technology by my LEA, along with funding for a mentor. I have had a much more positive experience getting ready for uni than I did at school!

Many thanks again.

Katy Brackston

graciously accepted your kind invitation to spend Christmas with your family. He isn't quite ready yet as he has to decide what he wants to bring with him. Don't spoil him too much when he arrives or he will be impossible to live with when he gets back!

Love to you and your family, Jennie

Joanna has also held her Local Education Authority to account: *I took my complaint about Patricia's education to the Local Government Ombudsman. I had help from a firm of educational specialist solicitors. After 10 months the Local Authority offered a settlement of £3040, after initially denying that there were any errors on their part, then admitting to some and then fully accepting blame.*

I have two girls with ME. I am Polish and moved to the UK twenty years ago. It's my home now although I do miss my country, with its gorgeous mountains, lakes and beaches. I have five cats - don't ask me how! I love them all but do they care? Cats are such independent creatures!

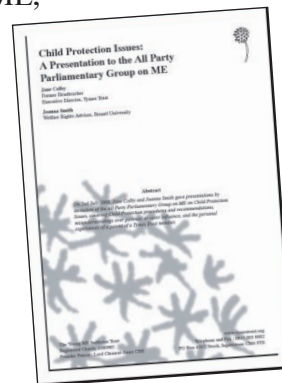
Joanna Smith Welfare Rights Adviser

We welcome Joanna both as Welfare Rights Adviser on our Professional Referrals Panel and as a member of the Advice Line Team.

In *The Brief*, you can read about Joanna's submission to the All Party Parliamentary Group on ME, in which she describes her own experience of an erroneous Child Protection referral.



I am a welfare rights adviser of ten years' experience and absolutely love my job. I am especially interested in sickness and disability benefits and how poor health affects people's income. I was trained by CAB but then moved on to



work in a Students' Union movement so I also have knowledge of Student Funding and hardship grants available to people in Higher Education.

Considering that each year hundreds

of millions of pounds are unclaimed in sickness and disability benefits, I am always shocked at how extraordinarily difficult it is to claim such benefits, the brick wall of ignorance that ME sufferers have to punch through to get support and - to add insult to the injury - the unfair treatment that recipients of such benefits get from some media.

I joined the Trust initially because I was desperately seeking help when our world went upside down due to ME but now I am happy to help to fight this type of benefit injustice and offer my experience as a welfare adviser. If I don't have an answer you are seeking, I know where to find it!



Jo-Anna Roberts
Advice Line Coordinator

We had a wonderful time this summer! We enjoyed exploring Snowdonia, and ended up staying at two very different but equally great places - a traditional B&B and an eco/green guest house that was run by

a couple with a daughter who has ME. Having rain, cloud, wind, and more rain (known as 'liquid sunshine' locally!!) wasn't a problem - in fact it gave the long windy drives a suitable atmosphere. We had a beautiful drive back in the sunshine - I drove from coast to coast - not that far (44 miles) but fun and the furthest I've ever driven!! Loads of lovely places to stop.



It was great to hear that Jo-Anna and Jon had managed to have a holiday away, despite ME. They have now bought two beautiful lovebirds.



YOUR CHARITY NEEDS YOU!

Two of our stalwarts on the Advice Line have moved on, Katy to begin university, and Penny, whom many of you will know (she has been with us for many years) because of other commitments. Please consider giving two hours a week (rather than two pounds a month!) If our Advice Line Team has helped you, you could help others in your turn. We provide full information and you'll be part of a great team of friends. We look forward to hearing from you.



Question Time!

On a busy October Saturday, over 100 people gathered in Colchester to seek the combined wisdom of the ME Question Time panel! The event was organised by the ME Association and the invited dignitaries were: Consultant Neurologist Dr Abhijit Chaudhuri, Trust Executive Director Jane Colby, dietician Judith Harding and MEA Medical Adviser Dr Charles Shepherd. Neil Riley, Chair of the MEA, had planned to take part but was unfortunately unable to be there.

The format of the day was the same as BBC Question Time, with all speakers addressing each question. This proved to be very successful.

Fundraising - Many Thanks!

Tendring ME Group, one of the Trust's Partner Groups around the country, has donated £500 as the Group is closing. We wish all the very best to Chris and Tony Baxter, who have run the Group faithfully for years. They will become Friends of the Trust. These funds are going towards the new project that the Trust is running with John Chia MD, looking at enteroviral infection in young people.

Westonbirt School The final total from the poetry and music evening was £200. Thanks to the school and to Sophie Baggs for their support.



Ardglass Golf Club, County Down

On behalf of our Captain Mr Charlie Bell and the members of Ardglass Golf club I have pleasure in enclosing two cheques to the value of £600. This money was raised on Captain's Day by the kind donations made by our members.





U 2 D o

Resident artist Susie Jayasinghe shows
you nature through the looking glass

Things 4



Look into
Susie's
kaleidoscope
and you'll find
ivy leaves,
berries,
flowers, tiny
buds starting
to open, winding creepers
and curling tendrils.
Colour the picture for a
special prize and we'll print
it if we have room. Susie
would love to see it brought
to life.

Write us a story, a
description or a poem

KALEIDOSCOPE OF THE SEASONS

inspired by the picture and
you could win a Shirley
Conran Writing Award.

Colour a photocopy if you
don't want to cut up Vision.
We'll return it if you send us
a large letter stamp.

Name

Age

Address

CHLOE'S SURVIVAL WORDSEARCH

M	A	W	S	H	E	E	P	B	E
O	L	E	N	D	A	S	I	A	N
U	B	B	O	B	U	O	T	8	D
N	B	R	W	O	N	S	I	L	A
T	X	E	L	S	Q	B	O	E	N
A	H	D	E	Z	X	U	P	G	G
I	Z	I	O	P	A	C	I	S	E
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S	E	S	A	Y	R	I	A	H	E
L	S	U	R	V	I	V	A	L	D
W	I	L	D	G	O	A	T	S	F

SNOW LEOPARDS live in the MOUNTAINS of ASIA. Their fur helps them to blend in with the SNOW. They feed on WILD GOATS and SHEEP. They have 4-5 CUBS. They are ENDANGERED because of HUNTERS.

SNOW LEOPARD

I've drawn you this really cute snow leopard. I don't know what his name is, maybe the *Vision* readers would like to guess?

Chloe Halstead

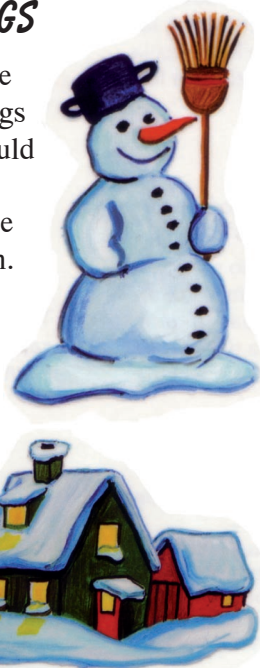
Give Chloe's snow leopard a name and win a prize! We've got some colourful winter gloves!



SNOWY WINDOW CLINGS

We've still got some winter window clings

if you would like some to decorate your room.



LISTENING LIBRARY

Don't forget that if you like reading but are too ill, we have negotiated free membership of the National Listening Library for members of the Trust.

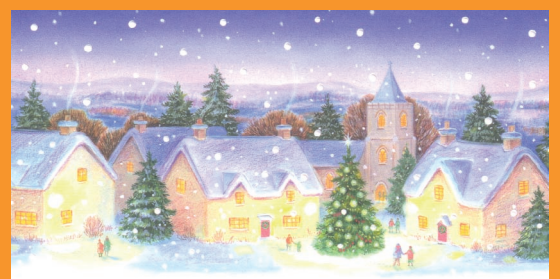


TEDDY LABELS

Message reads: We're supporting The Young ME Sufferers Trust.

Great to decorate envelopes. Or get our purple flower labels.

£1.25 per sheet or 2 sheets for £2.



Evening in the Village

As the sky begins to -----
And the night draws ever ----
To the hooting owl I hearken
Sometimes I feel awe and fear.

While the church bell rings the -----
All my family's -----
In the gloom I smell my flowers
From the windowsill I peep.

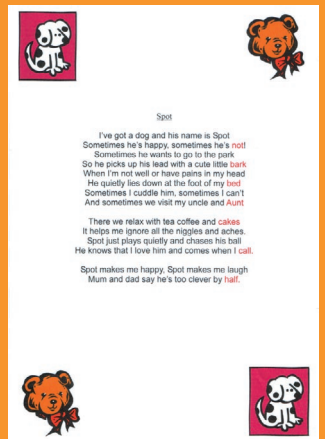
Look! A badger sniffs and -----
Digging in the earth for -----
Me, I'd rather chocolate truffles
Treats unsmear'd with mud and germs.

Whoops! Already it's late -----
Have I really slept this -----?
I dozed off when day was dawning
Cos my bodyclock's gone wrong!

Find the missing rhymes - you might need help this time! Count the dashes, one for each missing letter. In each verse, line 1 rhymes with line 3. Line 2 rhymes with line 4.

First prize: a personalised 2009 calendar for your room. Lots of other prizes. Draw us a picture to go with the poem and you'll get an extra prize.

Last time, Elizabeth Bell won for a second time. She laid the poem out again herself!





do you know anyone who would like to receive our email alerts?
 membership of the Trust is not required
 subscribe at www.tymestrust.org

Alerts are provided directly by Jane Colby, Executive Director of The Young ME Sufferers Trust. She was a Headteacher for nine years, a member of the government Chief Medical Officer's Working Group on CFS/ME and co-authored *ME/CFS In UK Schools*, the largest epidemiological study of ME to date. She is a member of the National Association of Educational Inspectors, Advisers and Consultants (now ASPECT), a life member of the National Association of Head Teachers and a Fellow of the Royal Society of Arts.

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Here are excerpts from the Alerts that have gone out so far. Join the free Alerts Club to make sure to get them regularly.

**JUNE 2008
 GOVERNMENT THANKS TRUST
 FOR INPUT TO NEW EDUCATION
 WHITE PAPER**

The Government has thanked The Young ME Sufferers Trust for our input into the new Education White Paper 'Back on Track : A strategy for modernising alternative provision for young people'. We are pleased to note the inclusion of virtual education in the White Paper.

At the invitation of Parliamentary Under-Secretary of State for Schools Lord Adonis, the Trust's Founder Patron Lord Clement-Jones, Chair Keith Harley, Executive Director Jane Colby and Director of the Nisai Virtual Academy (NVA) Dhruv Patel met with the Deputy Director of the Special Educational Needs and Disability Division of the Department of Children Schools and Families.

We presented the results of the education partnership between the Trust and the NVA in which children with ME obtained higher grades and better overall results using interactive virtual education than did healthy children attending school.

We also explained that children's educational rights are often over-ridden by the way in which their condition is medically managed.

The White Paper states: 'Where a pupil remains in alternative provision because they are not ready to be re-integrated to a mainstream or special school, it is essential that they nonetheless receive an education that puts them on the path to success in adulthood. This is not just the right thing for them, but for their local community and for society more widely.'

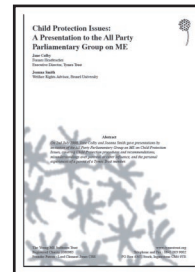
It continues '...we must learn from the best and support innovation.'

Chapter 7, 'Learning from the best and supporting innovation' speaks of 'building on what works'.

The Deputy Director of the SEN and Disability Division has written to Lord Clement-Jones: 'the meeting we held did inform our thinking. Please see Chapter 7 (from page 50) onwards where you will see in para 7.4 a commitment to run innovative pilot projects for alternative provision, including: "e-learning and virtual provision, particularly for pupils who cannot attend school due to health needs."'

The Trust has been invited to respond to the White Paper.

**JULY 2008
 TRUST PRESENTATION TO ALL
 PARTY PARLIAMENTARY GROUP
 ON CHILD PROTECTION ISSUES**



On 2nd July 2008, Jane Colby, Executive Director of The Young ME Sufferers Trust, together with Joanna Smith, parent and Welfare Rights Adviser to Brunel University Students

Union, gave a presentation by invitation of the All Party Parliamentary Group (APPG) on ME concerning Child Protection Issues. They covered Child Protection procedures and recommendations, misunderstandings over parental or carer influence, and the personal experiences of a parent of a Trust member.

You can read the full presentation at www.tymestrust.org/pdfs/childprotectionissues.pdf.

Jane first laid out the situation regarding Child Protection procedure and gave the Trust's recommendations to help stop their misapplication to the families of children with ME.

Trust Alerts Club

free trust news straight to your inbox

Jane then read out to the meeting the section on misunderstandings over parental or carer influence from the Trust's recent publication 'ME - The Illness and Common Misconceptions: Abuse, Neglect, Mental Incapacity', available at www.tymestrust.org/pdfs/metheillness.pdf.

This concise document describes the disease of Myalgic Encephalomyelitis, contrasts it with Chronic Fatigue Syndrome and explains why young people with ME are commonly misunderstood as being abused or neglected by their parents, or as lacking mental capacity to know their own minds and make decisions affecting their lives. It was written by Jane at the request of the Official Solicitor as a Judge's briefing.

Joanna Smith's presentation covered her personal experience of an erroneous Child Protection investigation.

Joanna has now joined the Trust's Professionals Referral Panel as our Welfare Rights Adviser.

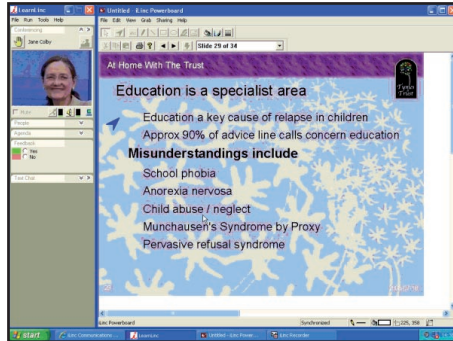
OCTOBER 2008 'AT HOME WITH THE TRUST': WATCH THE RECORDING; A VIRTUAL PRESENTATION WITH QUESTIONS AND ANSWERS

You can now watch this year's virtual 'At Home With The Trust'. The recording is at www.nisai.com/events/at-home-with-the-trust.

The At Home was held to celebrate the Trust's birthday this summer. It was hosted by the Nisai Virtual Academy.

After a short, illustrated presentation from Jane Colby, there follows a question and answer session, in which those taking part were free

to raise any ME-related issues. The event was designed for Trust members, their families and other interested people.



Jane has run training days for teachers, some organised by the Trust in conjunction with ASPECT (formerly the National Association of Educational Inspectors Advisers and Consultants, of which she is a member) and some organised by Local Education Authorities at which she has been guest trainer.

In 2007, she ran her first virtual seminar for a group of education professionals in Welsh schools. Some other areas also joined in. In one school, around 30 staff took part including teachers, the local Educational Psychologist, the Education Welfare Officer and the Special Educational Needs Co-Ordinator (SENCO). They watched the seminar together on a large screen. We were afterwards told that following the seminar, most stayed on for more discussion on the issues raised.

Because these events are interactive, people can ask questions about issues that affect them in particular. Feedback has been good.

Jane would be delighted to involve teachers and schools in a future virtual seminar for education professionals. Please contact the Trust if you would like invitations sent to education professionals

whom you know, once the plans are complete.

OCTOBER 2008 NEW: THE BRIEF (2008-2)

A new issue of The Brief, our regular information supplement by Jane Colby, is now online at www.tymestrust.org/pdfs/brief2008-2.pdf.

From today, the Trust will publish issues of The Brief on our website alternately with issues of Vision, so we shall have new publications for you more often than hitherto. We hope you will like this change.

OCTOBER 2008 NEW SELF-HELP PUBLICATION: EXPLAIN YOUR ABILITIES

This publication contains a questionnaire designed for you to complete and give to teachers or other professionals...

NOVEMBER 2008 WATCH THE 'YOUNG HEARTS' VIDEO ON YOUTUBE

For those who don't know the history, Young Hearts Day is when the Trust remembers all young people with ME everywhere, and you can commemorate it by watching this video: www.youtube.com/watch?v=ga3BphInA-E. It was made by young people in Scotland for Young Hearts Day (29th November).

PLAGIARISM ALERT

Sections of our APPG presentation were published earlier this year by another youth ME organisation without acknowledgement to the Trust. This is called plagiarism or 'passing off' as one's own work. To make sure you know when anything new is uploaded to our website, join the Alerts Club and read the original.

Jane Which came first, the ME or the writing? Did you always used to write?

Nasim I got ill when I was 18, so I was still a student. I wasn't really writing then, I was studying French and English. I didn't want to be a writer since I was five, or anything like that. My talent as a writer simply evolved from the chaos of being ill.

I do remember when I first got ill, I used to write my symptoms down because they were so crazy and changing and never-ending, and then I started keeping a journal. So having got the illness prompted me to start writing.

J That's very encouraging to people isn't it? You've turned it to something so positive.

N I think that so much about writing is observing. Even when you're really really ill in bed you can still be observing. Over the years without even realising it I was constantly observing things and when I started writing the book I was using all of that stuff from way back.

J You've been kind enough to record a poem out of our *Young Hearts* book, where young people have written what they felt about the illness - one of our Advice Line Team came to the flat?

N Yes, Lesley and her husband and her younger son, not the son who has ME, came to visit. We talked, and I recorded the poem 'Different' by Ana-Alicia Bryant. The reason I chose that poem was that I really liked the simplicity of the language.

I like language to be very simple, I think it's much more powerful like that. So that's the one I chose to record for the project they were doing for Young Hearts Day.

The thing about these *Young Hearts* poems is that, although different from my own writing, which was a ten-year project, they express pain and isolation and human dignity, not self-pity, there's no self-pity there. That to me is crucial because once it becomes self-pitying, you don't want to read it any more. If you can describe what you're going through without wallowing, that's very

important. Young children have managed to do that in *Young Hearts* so I was pretty impressed by that.

J I understand that as the Community School in Auchterrada were doing a project about this, it was your suggestion that some of the children should record some of these poems.

N Yes it was. To me it made sense that young voices were reading these poems. Then it has an authenticity about it. Lesley seemed to be keen on that idea and that's what they're putting together now.

J So with your novel, you say it was a ten year project.

N It was. The book was with me for so long. I probably started writing it in 1998. I really wanted to write about my illness, there was no question I wanted to do that, but I was adamant that I did not want to write my story or my memoirs. You're preaching to the converted. With ME,

there's so much misinformation being peddled around. I thought if I presented the story of a young character with ME through fiction it would make it more readable. More people would pick it up.

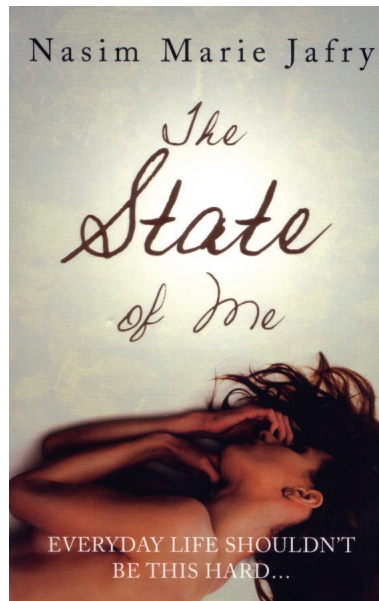
At the time I had no clue that it would ever be published. I just knew that I could write and it took probably six or seven years to finish because obviously there were a lot of hours and days and weeks that I couldn't write. I just wrote when I could. I had lots of ups and downs getting it published, but that's fairly typical.

J You called it an autobiographical novel, so it's a bit of both, isn't it?

N Yes. The main character, Helen, and I, we have the illness in common without a doubt, and probably the book is more autobiographical at the beginning because I got ill when I was abroad and it turned out to be the Coxsackie virus, but that took months and months to diagnose.

J Mine too.

N And the book is in three parts. Each part covers five years. I got ill in the early 1980s and the



Nasim Marie Jafry

jane colby interviews the author of *The State of ME*

buzzword then was 'You'll get better in five years.' It was hellish to get this diagnosis but we were all clinging to this; 'in five years I'll be better'. Which of course was nonsense. So I think that's why I ended up with three parts, each one five years, because in my own life I was measuring the illness out in periods of five years. I wasn't recovering the way I hoped I would.

Obviously there are aspects of my own life cut and pasted, but this is not my story, this is Helen's story. But I could not have written this book if I didn't have ME. You couldn't really invent that stuff or use someone else's experience. And a lot of my anger and hurt about the way the illness has been portrayed is certainly represented in Helen's character.

J There are some disability issues in the book too, aren't there.

N Yes, because it's a novel about a young woman whose life is cut down.

J But it's also full of her development. You've called it a 'rites of passage' book?

N I didn't say that myself - people label things - but I guess it is, because anybody changes between 18 and 35. Helen may be 20, but any young person is going to change between 20 and 35 and Helen certainly does. Some of it is my own experience but a lot of it is made up, it's what happens when you're writing.

Writing the book was hugely therapeutic as well. Sometimes I think it was a huge act of therapy to write the book. It's fantastic it's been published - I'm absolutely overjoyed - but if it hadn't been, I would still have had the book as my weapon against the world. This is a physical neurological illness.

J I was also interested in the granny who was so unbelieving. That's a problem that children often have.

N Yes. There are two grannies in the book. There's the granny who really believes and then there's the granny on the father's side. We've all come across members of families, not necessarily grannies, who don't believe in the illness. Or a close friend. It was very important to fictionalise that aspect. I thought that worked quite well.

J I did too. I was ever so pleased you liked *The Clangers*!

N Yes! There are a few references to children's programmes. There are aspects of childhood that are with you forever and you never know when they're going to come out. I could probably have used

any children's programmes but I referred to *The Clangers* - I just remembered them very strongly. I loved them! They're sweet wee creatures. When I think of *The Clangers*, it was a very happy, innocent time, there was no sense that this terrible illness was going to befall me. I think Mr Ben's in there too.

J Of course, we ought to emphasise - because our readership is young people - that the book is actually quite adult; particularly, there's some sexual content.

N Yes. It's never gratuitous, there's nothing untasteful. A young woman gets ME and a lot of young adults could relate to this, but there is some sexual content.

J Because she's growing up.

N She's growing up, and parents may want to read the book first and think about whether it would be suitable for their child or not. It's about a young adult. I would hate for any young person to be offended.

J Another thing I thought was that the language was so beautiful.

N Thank you Jane. And the people who've read it and have ME themselves love seeing all their symptoms in a work of fiction because that doesn't happen very often. But the people who don't have ME and who are reading it because it's been recommended, or whatever, they're learning a lot about the illness. I'm constantly getting feedback saying 'I didn't know it was this bad. I had no idea.' I'm also hearing that they love the simplicity of the language. People with ME find it an easy book to read because it's in small episodic chunks, it's broken up. That's how I wrote, because that's how I think, because my concentration is so crap! [Laughter]

J Do you have any future writing plans or are you having a period of rest?

N A period of rest just now. I'm recovering from the writing and the publication. I know I can write, that's something that I have, that won't go away, but at the moment I'm just resting.

J What this shows is that people with ME, even when they're not completely recovered, can achieve success.



Experiences

One of the young people who wrote the poems in *Young Hearts* went on to university to study Literature, partly inspired by seeing her poems in *Young Hearts*, and she's just got herself a degree.

N That's absolutely brilliant. In the book, Helen makes slowly, slowly, little recoveries, but that wasn't my experience. I was housebound for seven to eight years.

J I guess the launch was pretty exhausting for you.

N It was massively exhausting but for me it was the celebration of ten years of this bxxxxx book! I wanted to do it. It was great to have family and friends and people I didn't know, like Lesley, come along and be so supportive. It was really a lovely lovely evening and I'll never ever forget it. It was one of the highlights of my life. I'll always have that evening with me. People who don't know me probably think I came over as being well and having energy but you come home and you're absolutely wrecked!

J Wiped out.

N Absolutely. But it was fantastic. Brilliant.

J Is there anything you want to add?

N Just to emphasise that this is a work of fiction. Helen isn't me and I don't use my mixed race background. You can be more honest through fiction and present the character's vulnerability when you're not writing about yourself and how dependent you are. It would be impossible to survive this illness without support from friends and family. I'm lucky I've had that. I've also cut people out of my life, I think that's what we have to do if people are being derogatory or detrimental.

One thing I would say is, for God's sake don't overdo it. That would be my advice. Don't let anyone or anything pressure you into overdoing it because my experience is that everyone can be made worse by overdoing it. I think everyone has that in common, would you agree?

J Yes, I absolutely agree. It's part of the definition. If somebody doesn't find that's a problem...

N They don't have it!

*Find Nasim's blog at
www.velo-gubbed-legs.blogspot.com.*

Interview Copyright © Jane Colby

I have been a member with yourselves since I was diagnosed with ME eight years ago. Your magazine is so helpful and I remain hopeful every time I read about all of the research into ME that you support.

Unfortunately my GP isn't so helpful. When I was first diagnosed I was sent to a 'specialist' who referred me for physiotherapy. This worked on the concept that they would exercise me harder and harder each week, slowly building up my stamina. All this achieved was making me bedridden for several months. This was the only help I ever received and when I turned 16 I was too old to visit the specialist and was never referred to anyone else.

Emma Thompson

Physiotherapy (unless passive) is a common cause of relapse. Read Physios Urged to Go Cautiously in the Professional Guides section at www.tymestrust.org/tymespublications.htm.

Newspapers

tell them what you think - we did

Letters page, The Sun 12th May 2008:

It was a bad day for children when ME got called by the barmy name 'Chronic Fatigue Syndrome'. Some of our children can't speak or swallow and have to be tube fed. That is so not 'fatigue'. That is devastation.

Jane Colby

Executive Director

The Young ME Sufferers Trust

If you're affected by a period of severe illness and need information, do contact us. This letter was translated and reposted on websites around the world:

I've posted your brilliant letter on the homepage of www.cfs-aktuell.de (in German of course). It is so very much to the point that I think that those few words will tell people what this disease (ME) means.

Regina

Reposted your letter on my sites.

Antoinette Christie, parent and campaigner

Your Benefits

by joanna smith, welfare rights adviser

Illness is an expensive business; loss of income for sufferers of working age and their carers can hinder recovery. The findings of a Joseph Rowntree Foundation survey confirmed that families with disabled children face much greater financial difficulties than those who do not have these additional costs. It found that: 'The budget standards estimated an average cost of £7,355 a year to bring up a child with a severe disability. This is at least three times more than the amount required to bring up a child without a disability established in a study using a similar methodology.'

We cannot increase our income by taking on more work or moving up the career ladder. Often we are the sole carer of more than one person; child, disabled child, elderly relative or ill partner. We have no option but to apply for benefits.

The Trust's Advice Line has details of organisations who can help you identify benefits you may be entitled to, and as a member of the Trust's Professionals Referral Panel I can talk your situation through with you.

Preconceptions about claimants, particularly with regard to ME, are common (see page ii of *The Brief*). There is prejudice and misunderstanding which finds its way into the media. However, the audited estimate of fraud in sickness benefits is under one per cent. If you need help, do apply.

The system is complicated. So here are some tips.

You can still claim Child Benefit if your child is over 16 and suspended education due to illness or disability.

If you receive Income Support, Job Seekers Allowance (JSA), Housing Benefit, Tax Credits and you or your child receives Disability Living Allowance (DLA) you are entitled to a 'disability premium' - an addition to your benefit which can be substantial. Check your benefit award notice or call the department that issues your benefit or Tax Credits to confirm this.

Apply for DLA for your child and for yourself if you have ME too. There is no need for formal diagnosis. However, DLA is

designed for people who need help and assistance for at least one hour a day, so you do have to need it.

If you're unsure whether you are entitled to a certain benefit, always apply, as waiting can mean that you are losing money to which you may be entitled. If you are refused, consult an advice agency to see if you can appeal or if the refusal was correct. I have found that, unfortunately, the staff at official helplines (Job Centre Plus, DWP) don't always get it right.

Find time to go over all your benefit and tax credits; check what you are receiving and then check whether you could be entitled to anything else. To find out, you can contact Community Legal Advice (0845 345 4345; www.communitylegaladvice.org.uk).

Joanna Smith is a Welfare Rights Adviser at Brunel University Students Union. She has two children with ME.

NHS in the East of England

statement by barbara robinson, east anglia ME patient partnership

All groups and charities in the East of England recognise and have been vocal about the current failings in NHS Services to people with ME, nationally and regionally.

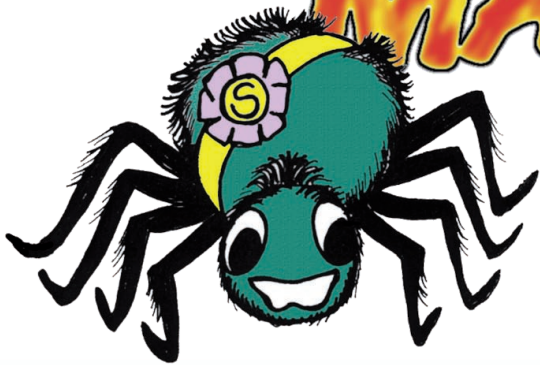
The Young ME Sufferers Trust is the leading children's charity nationally in the local patient group's view, especially in regard to children's rights, safety and access to appropriate services (Health, Social Care and Education). The Trust has fought for access to appropriate

health services, diagnosis, treatment and care for children with ME.

Strategic Health Authorities (SHAs) used public consultation as part of their planning for the next decade. The Trust, other East Anglian Groups and charities have responded. Local County politicians have formed a Joint Regional Health Scrutiny and Overview to evaluate the SHA's plans. This forum can have legal powers to investigate if there is a problem with the

SHA's vision. This is what we are requesting from them. The Trust's publications *Our Needs Our Lives* and *ME - The Illness* are providing part of a powerful 'evidence base' logged with the Scrutiny and Overview. ME patients and groups feel that Government guidance *National Service Framework (NSF) for Long Term Neurological Conditions* (2004) is not being complied with and that NSF quality requirements are not being met by Primary Care Trusts (PCTs).

SEB'S MANOR



Sebastian Says

Welcome to my Grand Exhibition! All the art I could get my legs on! As a highly esteemed Patron of the Arts, I hereby announce that I have decided to appoint Ms Chloe Halstead as the Trust's Young Artist. I am also accepting her invitation for Christmas. It will be a serious visit so that I can observe her at work. The obligatory seasonal nosh-up has nothing to do with it. Really. Nothing at all.

I need to say a special thank you to Rosemary Lever for very kindly helping me re-stock my official Treasure Chest:

I hope you can put the enclosed to use, perhaps as prizes for letters to Vision or to cheer up the bedridden. All the best, Rosemary

I'm in charge of all the prizes of course, so why not enter my competition so I can send you one. I always reply to everyone who enters, which is easy because I can use eight pens at the same time.

Now Toby Rawson doesn't know this, but when he was looking for a penfriend, I helped Jennie find him some. Wahay! I am a spider of many talents. And a poet of considerable note too of course, let's not forget that. And modest.

I would just like to say that I have received your letter and would like to say that several people have contacted me and that I am chatting to them. Thank you for all that you have done. =) Toby (12)

You're most welcome Toby.

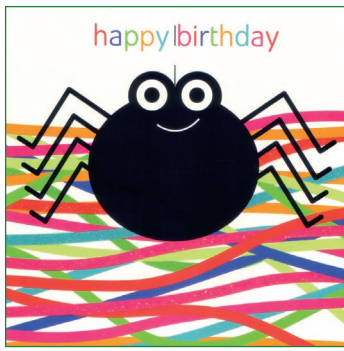
Due to a relapse I have found myself needing to do some relaxing art work. So I have been painting and making cards. I know you pop cards into the Christmas edition of the mag so I hope you can use the small Christmas cards I have sent you. I have enjoyed making them.

Mary Jemma Lee (26+)

Thank you SO much Mary - I think they are fantastic! All the cards we send are personally signed by Jane, but these ones are so good I think I'll do them myself.



If you like the card you get from us this Christmas, why not send us a photo of yourself with it?



To Seb,
Happy Birthday
from Cheryl!!
Fudge says happy
birthday too. Have
a weberly birthday.

Lots of hugs from
Fudge and Cheryl
x x x

To Seb
Happy Birthday
From Cheryl Fudge says
Happy Birthday too
Have a weberly Birthday
lots of hugs
From Fudge and Cheryl
x x x

Seb's Grand Art Exhibition

I drew this card with them and I think it looks effective!
Thank you also for the superb birthday card, I really cheered me up!
I got a camcorder for my birthday and have been filming everything! I also got a gorgeous cuddly lion called Barney and a toy hamster called Ojo.
Thank you. You make me feel SOOO special!
Love Chloe
(Hobstead)
16. VERY YOUNG AT HEART.
Euphrasya Hobst
7 Edmond Coast
Colony Hill
Colonia
CMA 900
01328 6000.



Thank you so much for the super, fantastic incredible and awesome MAGIC pens! I love them! And so does my mum. And my sister. And Dad. Honestly, with all of us sprawled out on the bed scribbling away, it's a wonder we didn't stain the duvet with the pens. Even the cats had a go! I drew this card with them and I think it looks effective. Thank you also for the superb birthday card, it really cheered me up. I got a camcorder for my birthday and have been filming everything! I also got a gorgeous cuddly lion called Barney and a toy hamster called Ojo.

Cheryl remembered my birthday! How kind. She must have put it in her diary or mobile. (It's June 15, by the way...)



The cheeky kitty shouting is Hamish Claw
The others are Lilly and Jamie Claw



And Dad. Honestly, with all of us sprawled out on the bed scribbling away, it's a wonder we didn't stain the duvet with the pens. Even the cats had a go! I drew this card with them and I think it looks effective. Thank you also for the superb birthday card, it really cheered me up. I got a camcorder for my birthday and have been filming everything! I also got a gorgeous cuddly lion called Barney and a toy hamster called Ojo.



Thank you. You make me feel SOOO special.
Love Chloe

I like to make you ALL feel special. Do write to me - I love letters. And emails! I don't care how old or young you are - let's not be ageist about this!



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



WORD SEARCH

see page 13

As well as all the artwork (she even drew all over the envelope, how about that!) Chloe sent me a Winter Word Search. However, being a highly articulate arachnid (did I mention that?) I found a few gaps to put in some extra words of my own. Can you find them? I have some special wordy searchy prizes waiting.



A poem from...

Laughter Helps

I know from the outside my life looks pretty grim,
Being me can be horrible, I wouldn't know where to begin.

But we always laugh and joke, and make up little songs,
Most giggles are caused by Mum trying to sing and going very wrong!

When the awful side of ME shows, like in the middle of the night,
That is when the Christmas carols come out and are sung with all our might.

Sometimes the jokes go over my confused head, I can be a bit dense,
I must admit most jokes are normally at my expense!

Like my nodding dog head, jumbled up words and completely mixed up brain,
My own foreign language and bed hair like I've been pulled backwards from a drain.

Or being teased I can hear what's said in Ecuador in the middle of the night,
Or that I must be a vampire because I sleep all day and I can't stand the light!

I don't mind really, sometimes you have to laugh otherwise you'd cry,
Sometimes these little snippets of madness are all that stop me from asking, why?

So yes, ME is awful and daily life can be very grim,
But a little song and laughter brings a little light from within.

Emma Gray

A Poem About My Illness

I have ME, so they say,
Those two letters go round and round my tiny brain.
What is it, I ask?
Why have I got it? I haven't done anything wrong!
My friends won't talk to me any more,
They don't want to know me in case I'm infectious.
I have tried to explain it to them, but they just don't listen.
All they can do is point and laugh at me,
Yes, that's the girl, the one who doesn't come to school.
They sometimes see me at the weekend but not very often,
And it hurts me to think that they used to be my friends.
They don't see me during the week, they don't come and visit me,
So how can they judge what I'm like, when they only see me occasionally?
They didn't used to judge me like this, so why now?
I can't go out to play or join in any games for I haven't got the energy.

I have ME, so they say,
I can't control it nor can I cure it.
I watch people go past the window,
All I can say is 'Why me?'
Why do I have the thing they call ME?

Jenny Katcher

*Jenny wrote this poem some years ago. She is now married.
She is delighted we are publishing her work.*

Every
thing
I want
to
remember
is at
the top
of a
deep
hole
I am
at
the
bottom
trying to
climb to
my
memories.

When I
climb I
try
and
reach for
things

That I
remember,
these
seem
to
move
further
away
to
the

Top
of
the
hole.
I seem
to be
able to
grab
a few
memories

The rest just
float
away.

**Jade
Smith**

A letter from...

We love to hear from members who have been with us for years, to see how they are progressing. Do let us have your news.



I just wanted to contact you to say a big big thank you so much for being there when I needed help the most. I have just graduated from university this week with a 2.1 degree in English Literature, and this time 4 years ago I never would have believed it possible.

I became ill with ME 8 years ago when I was 14 and had it for about 5 years. Receiving your magazines made me realise that I wasn't suffering alone, and helped me to understand the illness a lot better.

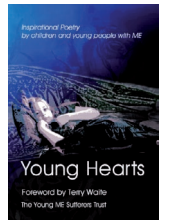
You also gave me my first taste of what it was like to have my poems published, and this I also thank you for as it was one of the things that helped me realise my love for creative writing. So I thought I would let you know that I am better now and I think what your charity does is a wonderful and helpful thing as ME is such a misunderstood thing and you help people realise that while also helping those young people who suffer from it. So thank you.

Rachael Marshall



Rachael's beautiful poetry is in our book *Young Hearts*, which was launched by Terry Waite in Warwick Castle on the very first Young Hearts Day, 29 November 2004. There's a short TV interview at www.tymestrust.org and if you'd like a copy for yourself or as a gift, you can order using our online Donations Form.

Price £7.95 including post and packing.



An adventure from...

Hello! Thank you very much for my birthday card it was a lovely surprise. I had a great birthday. I had a couple of friends and family round in the afternoon for a ceramic painting party. Because it was my 21st mum and dad are taking me to London for a weekend to visit London Zoo we may take Max the befeater bear. We



were both very excited when we saw the last article about me in print - it made me very happy to see.

Love Cheryll
x

We had a great trip. As you can see we had lots of fun with Max, Fudge was a little jealous that she couldn't come, but understood she had to take it in turns. She was just pleased to get Max back safe and sound after she heard about the danger Max had been in and how Cheryll rescued him.

Best wishes

Love Cheryll and Julie x x





Mr Harley's Pup-Keys More useful than the average bear?

You'll remember that every year, Chair of Trustees Keith Harley presents his annual gift of Bears. We've had Beefeater Bears (Cheryll Neyt recently took hers to London, see page 22) Bobby Bears, Beanie Bears, Big Apple Bears, Monsieur Le Blanc Bears from Switzerland...

This year Mr Harley fancied a change (which he is entitled to, he says, because he is Chair of Trustees). So he arrived with a plethora of puppies (that means more

than we can cope with). They're all hanging around waiting for good homes and none of them have names. What we haven't mentioned yet is that they all have key rings on their heads. Honest. They're running around nicking all our keys to put on them. We can't get into our houses half the time. It's chaos.

If you'd like to offer a home to one, write or email using the form at www.tymestrust.org (if you're not well enough, your parents can do it for you). Send us a photo of him in his new home and we'll publish it. And if he has a key on his head when he arrives, please send it back.

Young Hearts Day

Have you seen the Young Hearts Day poster at www.tymestrust.org? It was designed by Isobel Williams.



Tymes Trust's Young Heart's Day.

29th november

a day to think of the hundreds of children suffering from ME. give a little time.

Trust in Virus Project with Dr Chia

The Trust is working to ensure that the enteroviral cause of classic ME, as revealed by eminent researchers in the mid twentieth century, but subsequently ignored, is properly recognised so that antiviral drugs can be produced to fight the infection.

Earlier this year we had a two hour meeting with virologist Dr John Chia of California. In consequence, the Trust has set up a scheme whereby samples from our members may be analysed for enteroviruses by Dr Chia in his laboratory in California. We have sufficient funds to meet the costs involved in the analysis in some cases.

FACT

Clusters of ME are common in families, schools and communities. But many families are told that their children are just copying their brothers, sisters, or parents to get attention. At www.tymestrust.org you'll find free publications for doctors and schools.

At our request, a protocol for taking the samples has been drawn up by Dr Chia and provided to us. Already, the results of the first cases have proved positive. For further information, please contact the Trust on 0845 003 9002.

Read an interview with Dr Chia in The Human Factor (a preview of The Colby Report) at www.tymestrust.org.



ME is the biggest cause of long term sickness absence from school. It is a serious, potentially severe and chronic neurological illness. World Health Organisation classification ICD10 G93.3