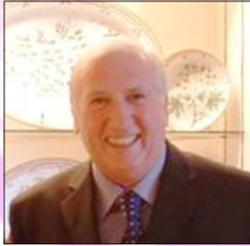


Mini Vision

POST-A-POSTER CAMPAIGN :

DON'T MAKE ME FAIL

AT SCHOOL



Why are school holiday periods the quietest on our Advice Line? Our experience, confirmed by clinical

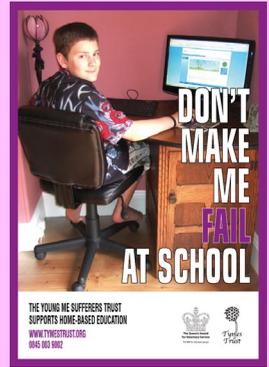
experience, is that school attendance is a key cause of ME relapse in children, echoing the Dowsett and Colby study finding that ME is the biggest cause of long-term sickness absence from school.

The Department of Health Report on CFS/ME (2002) stated: 'Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. [...] This may require information and communications technology, which can also help improve social contact.'

MYTH : Home-based education needs the recommendation of a consultant paediatrician

A GP is a qualified doctor and can confirm that a child is not well enough to

The Young ME Sufferers Trust



benefit from school attendance. There is no legal requirement for a consultant's report. This was confirmed to us by the Parliamentary Under-Secretary of State for Schools in 2006 and we are informed that it remains the situation.

MYTH : Progressively increasing school attendance promotes recovery

In effect, this is the educational equivalent of Graded Exercise Therapy (GET). In 2011 I wrote to you that 'children pushed into graded school attendance too soon typically relapse.' Yet some consultants tell schools to enforce this, possibly unaware of every child's right to suitable education provision, which is the legal duty of the school and the Local Education Authority. Once a child is strong enough, increased school attendance can follow.

Inside, we explode more myths.

Kindest regards,

Keith Harley
Chair of Trustees

2012-2

House of Lords Education Awards

A big thank you to our founding Patron Lord Clement-Jones CBE for hosting our Education Awards in partnership with the Nisai Virtual Academy at the House of Lords. Arron Sleep, featured on our latest information

poster, was awarded the Outstanding Progression Award and his brother Lewis the Dedication to Education Award. For health reasons, they were unable to attend but everyone applauded them. Four of the Trust's Young Officers also received certificates, along with NVA students with other conditions. It was a very enjoyable day and we launched the Trust's formal Statement on Virtual Education, which is on the back of the poster.



Lord Clement-Jones presents Sarah Coulbert, Young Officer of the Trust, with her certificate



*Jozef Mackie,
Young Officer of the Trust*



Dhruv Patel, CEO of the Nisai Virtual Academy



*Jen Flynn,
Young Officer
of the Trust*



*Shannen Dabson,
Young Officer
of the Trust*





*The Countess of Mar
Patron of the Trust*



*Ian Swales MP, Vice-Chair,
All Party Parliamentary
Group on ME*

*John Whittingdale OBE,
the Trust's constituency
MP, with Keith and Jane*



*Jenna
Rogers,
Tymes
Trust
Advice
Line*



DON'T MAKE ME FAIL AT SCHOOL

THE YOUNG ME SUFFERERS TRUST
SUPPORTS HOME-BASED EDUCATION
WWW.TYMESTRUST.ORG
0845 903 9002

*Lewis Sleep (below) and brother
Arron (above, on poster), students
of the Nisai Virtual Academy*



Why home-based education helps

Leaflet James CBE Executive Director
The Young ME Sufferers Trust
Speaking at the House of Lords
No wonder students with ME find concentration difficult. When the student makes an effort, oxygen levels in the brain can fall (many of these cope with the demands!). Obviously it can be next to impossible to study effectively after struggling into school.
Research also shows blood glucose concentration with a persistent viral infection. Many such facts about ME are not well-known and this leads to all kinds of misconceptions. Students can be thought lazy or just awkward, when they are doing their very best. Others will not realise why the student can't get to school at all, or can't concentrate on their work when they get there.



Statement on virtual education

James CBE Executive Director
The Young ME Sufferers Trust
Speaking at the House of Lords
As a former Head Teacher, I was author of the first specialist article on ME in a school/college. I also co-authored the largest ever study of ME in schools. This survey encompassed 1069 schools, 33,824 pupils and 27,517 staff – the largest epidemiological survey of this type made to date. It revealed that ME is the biggest cause of long-term sickness absence from school in both pupils and staff.
Although we have created resources to help with education in schools⁽¹⁾, our personal and professional experience and also my research have shown that for many people with ME the most effective form of education is home based, with interactive virtual education providing greater support, or higher than, health equivalents at school. Social contact is provided by online student groups, and where possible, interactions with the local school.
Such a protocol enables very sick students to achieve, when otherwise they are typically condemned to a recurring pattern of school attendance and subsequent relapse with little to show for it. They often feel they are failures, when in reality it is the educational system that has failed them.
Such a protocol has also been shown to preserve the student's health and recovery, in contrast with misguided pressure to 'back to school' years.



- [1] Effects of mild exercise on cytokines and cortisol blood flow in chronic fatigue syndrome patients
Diurnal PLoS One, Sleep, 2013, November, 10(4):1-2222
 - [2] The School Child with ME
Collis J, British Journal of Special Education 1992 39(2): 120-124
 - [3] Long Term Sickness Absence due to ME/CFS or UK schools
An epidemiological study with medical and educational implications
Diurnal PLoS One, Sleep, 2013, November, 10(4):1-2222
 - [4] The SENCO's Key Role in Supporting Pupils with CFS/ME
<http://www.youngme.org.uk/wp-content/uploads/2013/07/13-07-13-SENCOs-Key-Role-in-Supporting-Pupils-with-CFS-ME.pdf>
 - [5] The Tymes Trust Advice Line
<http://www.tymes-trust.org.uk/tymesadvice.php>
- The Young ME Sufferers Trust
Executive Chair 100005
Foster House, Leaf-Lovings Lane CH1
www.youngme.org.uk
0845 903 9002
PO Box 4147, Stock, CH4 4PT
-

Orsolya, Arron Sleep, working at home

More ME myths exploded

We were so sad to hear of the death of the great microbiologist Dr Elizabeth Dowsett, with whom Jane Colby worked closely. Betty was arguably the greatest ME expert of her time,



The last time Betty and Jane met, in the informal setting of a Tymes Trust Garden Party

and her vast knowledge of classic ME was the basis for all her advice to patients. In Jane's September talk to the Colchester ME group, she

quoted as follows from Betty's work.

MYTH : ME requires treatment to improve

The main principles of management rely on:

- *conservation of energy*
- *reduction of stress*
- *simplification of work*

This is an illness best managed by the patient at home once it has been fully explained and investigated. However, a great deal of support is required from an early stage if stabilisation at a functional level is to be achieved.

From *There's no smoke without fire!* by Dr Elizabeth Dowsett
www.tymestrust.org/pdfs/nosmoke.pdf



Colchester ME group hosted Jane's recent lecture on ME management with reference to the work of Dr Elizabeth Dowsett

MYTH : Rest is bad, and returning to school early is good

Children with ME suffer more severely than adults from disturbances of sleep, appetite, emotional control and cognitive ability ... [it is necessary] to promote rest, home tuition and family support.

From *ME escapes the myth of hysteria* by Dr Elizabeth Dowsett, published in *Hospital Doctor*, May 3rd 1990.

Moving on online

The Trust's online services include monthly email Alerts from Jane (register at www.tymestrust.org) and instant news and comments on Twitter which you can follow @JaneCColby.

To commemorate Dr Elizabeth Dowsett, we have now published online *There's*

[ALERT 2012-07 HOW TO MANAGE YOUR ME](#)
[ALERT 2012-06 DR ELIZABETH DOWSETT RE](#)
[ALERT 2012-05 STATEMENT ON VIRTUAL EDI](#)
[ALERT 2012-04 PLEASE DON'T WAKE ME UP](#)
[ALERT 2012-03 DO TREATMENTS FOR ME/CF](#)
[ALERT 2012-02 CRUEL COMMENTS SHOULD](#)
[ALERT 2012-01 GUARDIAN DECLINES LETTE](#)

no Smoke without fire! Some comments on the tendency to relapse in ME, which was written for our print magazine

in Winter 2000. Betty covers:

- What is a relapse?
- Are young people more at risk of contracting ME now than in the past?
- Why does ME take such a long time to stabilise?
- Are there any implications for management?
- How can a relapse be distinguished from a minor variation from 'normal'?
- What is the best way to manage a relapse?

www.tymestrust.org/pdfs/nosmoke.pdf

Have you read these?

Quick Tour of ME Symptoms, Management and Tymes Trust Services

'Mum uses your leaflet to explain the illness to people, like my care manager. It's the best leaflet on ME we've seen!'

www.tymestrust.org/pdfs/quicktour.pdf

Special Problems of Children with ME and the Enteroviral Link

Review of ME in children by Jane Colby, *Journal of Clinical Pathology* 2006.

www.tymestrust.org/pdfs/specialproblemsofchildrenwithmecfs.pdf

Explain Your Abilities

Contains a questionnaire for you to complete for teachers or other professionals.

www.tymestrust.org/pdfs/explainyourabilities.pdf

Alert 2012-06 Dr Elizabeth Dowsett remembered - an interview

www.tymestrust.org/txt/alert201206drelizabethdowsettremembered.txt

Speech to the Royal Society of Medicine by Shannen Dabson, Tymes Trust Young Advocate

From the 2009 Royal Society of Medicine conference 'ME and CFS - Hearing the patient's voice'

'If I'd have gone the conventional route I may not now feel so optimistic and in control of my own life. I would not have the good friends and role models. I would not have my qualifications - 6 GCSEs. Instead, I may just have short spells of school attendance between relapses!'

Shannen is now in correspondence with government ministers on the Trust's behalf.

www.tymestrust.org/pdfs/shannendabsonrsm.pdf

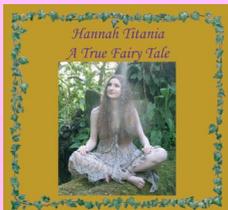


Shannen with Jane at the House of Lords

U2Do

Things 4

Limited Edition of her book *Hannah Titania : A True Fairy Tale*. Runners up all receive the purple First Edition.



We thought you'd like to see the winning entries

from Hannah Titania's fairy competition. First prize is a signed and numbered Gold



Chloe Halstead
Artwork Winner



Tara Mawer
Artwork Winner



Kathryn from South Africa *First Prize*



Fairies

*It was just a glimpse,
I can't believe it!*

*I squeezed my eyes tight,
The light was so bright!*

*Their song is heard by just a few,
So quiet it is almost missed.*

*If I listen carefully
I can hear their sweet melody.*

They know when to appear

When you are most in need

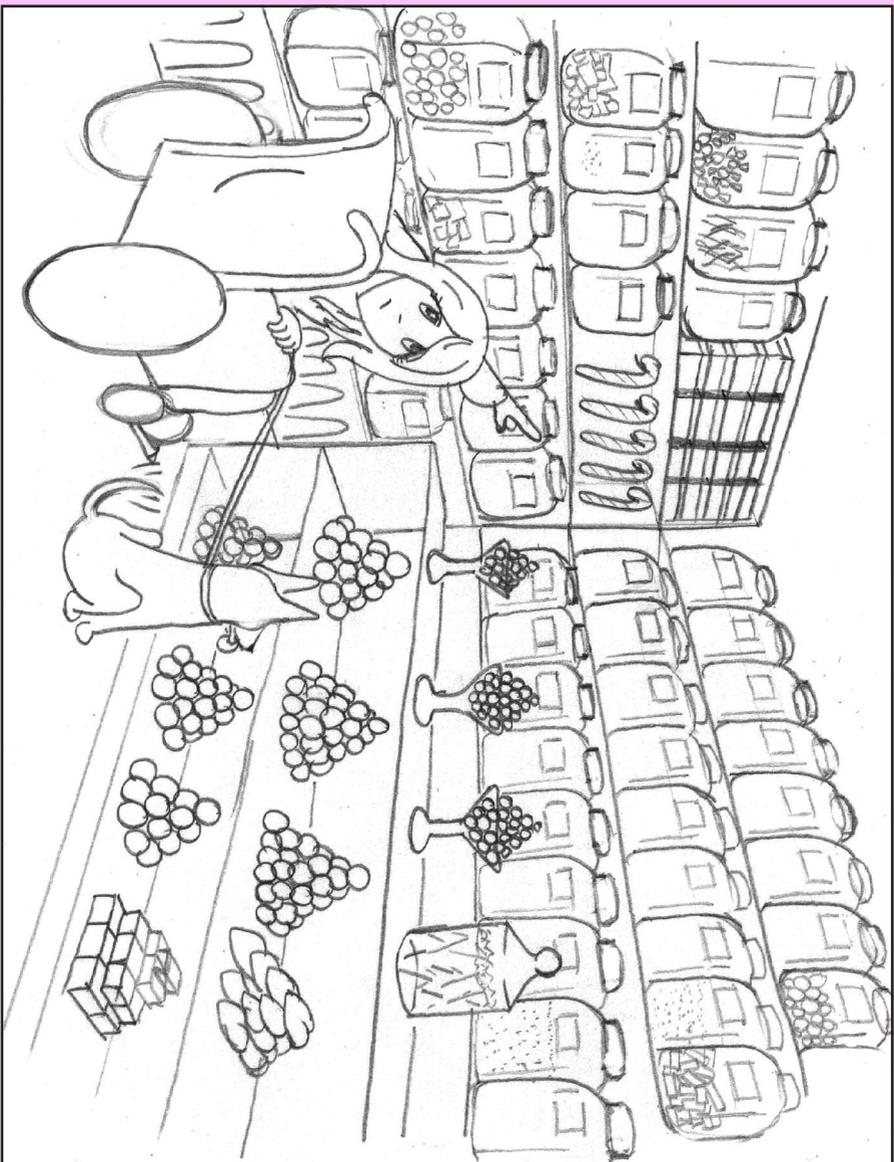
So trust in the Fairies

They are not just in stories!

Hannah Barnes *Poetry Winner*

COLOUR GREGORY'S SWEETSHOP!

Send your colouring to us for a prize. Include a stamp if you'd like it returned, and don't forget to add your name and address!

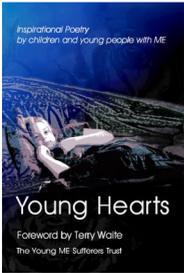


PRIZES FOR THE SEVERELY ILL

Gregory and Anita say: If you're too ill to colour, imagine going to this shop for your favourite sweets. Get mum or dad to write or email us about your fantasy trip. The Contact Us form is at www.tymestrust.org.

Name

Address



Young Hearts Day

Send us
your poems
to publish.
Lots
wanted!

commemorate the occasion
on Young Hearts Day.

Order your copy of Young
Hearts for £7.95 from
Tymes Trust.

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

**We love to hear from our
poets with their news...**

On 29th November 2004
Trust patron Terry Waite
CBE launched Young
Hearts, our book of poetry
by young people with ME, at
Warwick Castle. Each year we



My ME

Why do all these sounds seem so loud?
And my mind sometimes feel like cotton wool
Why does my head hurt so very much?
And my skin sometimes feel tender to touch
Why do I feel weak like a floppy rag doll?
It's all eating away at my life like a black hole...

Rachael Marshall

*Rachael went on to gain success and
obtain a degree in Literature, having
been inspired by seeing many of her
poems published by the Trust.*



A Mother's Eye View

My daughter dressed herself today
'That's very good' I hear you say
'If she is two, or nearly three.'
She's thirteen - and she has ME.

Such small achievements now, our aims,
Not 'top in maths' or 'good at games'
For that's the way it has to be
When you are coping with ME...

Gillian Stephenson

*Gillian has sent us
wonderful news of her
daughter's marriage.*

Win our Young
Hearts Day
eco bag with your
poem! It doesn't have
to be about ME.

Post it as soon as possible to:
Young Hearts Day Poetry, Tymes
Trust, PO Box 4347, Stock, Essex,
CM4 9TA or email us on the Contact
Us form at www.tymestrust.org.

