



ME Awareness 2013-2014

General awareness among professionals of how to care safely for children with ME while they heal is, in our experience, very patchy. Tymes Trust has had sight of a disturbing regime provided by a well-known hospital to a family whose child has ME. It includes instructions on waking the child early from sleep and on doing the same amount of activity every day, despite symptoms.

This regime would be contraindicated for children with ME, according to expert doctors with whom we work, and to the personal experience of countless families. The National Institute for Clinical Excellence (NICE) Guideline on CFS/ME clarifies that nothing is curative, and that there is no obligation to accept treatment.

Moreover, NICE states that if patients and families decline to take part, this should not interfere with

relationships with their doctors. Yet we are told that a home tutor has reported another family to social services because they withdrew from such a scheme. She seems unaware of NICE and the family may unfortunately need to report her if she persists in interfering beyond her professional competency.

Many 'prescribed' regimes are, according to parents and the young people themselves, counterproductive.

Remember that parents have the right to manage ME in the way that helps their child most. We have lovely letters and emails from families saying how much more effective they have found general convalescence to be, versus inflexible regimes.

Kind regards,

Keith Harley
Chair of Trustees

It is cruel to wake a child early and open the curtains to admit bright light. The child's brain needs time to heal.

Dr Alan Franklin

'Thank you for my snowy winter bear. I really like him. I have called him Mr Harvey.'



*Daniel Scaddan (8)
with one of Mr Harley's
Snowy Bears*

ME Awareness Day 2013 : How Things Stand

Research: What causes ME?

We feel it is vital that enteroviral studies by Dr John Chia of the Enterovirus Foundation in America be repeated in the UK. Over ten years, his work has demonstrated, just as microbiologist Dr Elizabeth Dowsett always maintained, that ME is

a persistent enteroviral infection. So it could be treated by enteroviral drugs (yet to be developed) and vaccination could also be possible.

This is the priority area of research in our view. However, when we raised

the matter of enteroviral studies in a meeting with the Medical Research Council, they showed no interest.

We therefore have little confidence in the MRC in this respect, which is a matter of serious regret.

ME (myalgic encephalomyelitis) v CFS (chronic fatigue syndrome)

ME specialist Byron Hyde MD stated in his book *Missed Diagnoses*: 'Patients are now being diagnosed with CFS as if it were a disease. It is not. It is a patchwork of symptoms that could mean anything.'

He emphasises the importance of identifying what is underlying the symptoms; does the patient have a sudden-onset virally

based disease (a typical ME presentation) or another as yet unidentified disease? Fatigue itself can be a symptom of major organ disease, or depression, whereas Post Exertional Malaise (becoming ill after effort) is typical of ME.

The latest doctors' guide to detail ME as a separate condition is the *ME International*

Consensus Primer from an international panel led by Professor Bruce Carruthers. This recommends Tymes Trust for education advice. Our Dublin partner group has arranged for Dr Ros Vallings, one of the authors, to give four talks in Ireland in May. For details, contact the Trust.

Child Protection Implications

The March APPG Group meeting minuted Tymes Trust's finding that both the severity and chronicity of ME/CFS can trigger child protection investigations. If the illness is severe or of long

duration, even an original diagnosis of ME/CFS can become suspect because of the perception that ME/CFS is neither that severe nor that long lasting. The number of erroneous child protection

investigations the Trust has helped with over recent years had gone up to 96 as of the meeting date. Contact us immediately if you think social workers are investigating your situation.

Fatigue Clinics are not ME Clinics

In 2002 the Department of Health published a report on CFS/ME, with which we assisted (Jane Colby was on the children's panel). We did not, however, like the report's recommendation for services, which we thought would be 'chronic fatigue' based. This is what happened. Despite some clinic therapists helping families in their dealings with schools, most seem

to follow a standard line in psychological therapy and graded exercise regimes. Many seem unable to grasp the seriousness of ME, which is potentially severe and chronic, and easily made worse.

The new Lothian fatigue clinic was set up against the wishes of patients at the Scottish Cross Party Parliamentary Group who voted overwhelmingly in favour of an ME centre of

excellence like neurologist Dr Abhijit Chaudhuri's former Glasgow-based service. His specialist ME clinic also referred doubtful cases for tests, and other appropriate care. But patient groups pressing for ME services have typically ended up with the fatigue model being rolled out everywhere. It is important never to suspend your own judgement when visiting such a clinic.

#AskTT / ME Awareness Day / Sunday 12 May 3PM-5PM BST

After the popular 'Ask Tymes Trust' Twitter Q&A held on Young Hearts Day, November 2012, a second session

is scheduled for ME Awareness Day. Tweet your questions to @JaneCColby and include hashtag #AskTT.

As with the first event, the questions and answers can be seen at any time later via #AskTT.

Managing Education and School : Webinar for Local Authorities, schools and parents

In a webinar at the Nisai Virtual Academy Hub in Harrow, Jane Colby presented 10 slides on the 2013 government Statutory Guideline on education for children with health needs who are unable to attend school

full- or part-time. She has now recorded a talk based on the webinar. Some comments:

Mary Schweitzer Ph.D. Philadelphia: *Magnificent!*
Suzie Henson-Amphlett: *This is FANTASTIC!*
Thank you! I have spent the

morning forwarding it to heads, teachers, Ed psychs, school nurses etc in the hope that they will forward it on to colleagues. Barbara and Sophie: *Thank you for this - trying to get across to people just what an impact ME has on someone's life*

continues to be a struggle. Unless someone experiences it, they cannot truly understand it seems. Sue, Walsall ME Link: Thank you for sending through this important information and for championing the needs of such vulnerable children. Sharon Cox: Congratulations on your amazing webinar on the school issues. I found it really useful.

In just 25 minutes, Jane's talk shows how the new guideline helps children with ME. She comments:

ME can be so severe and chronic [long lasting] that the education system has great difficulty coping with it. As a former Head Teacher, I understand that. But Local Authorities (LAs) must comply with the guideline, which is called Ensuring a good education for children who cannot attend school because of health needs.

The guideline applies whether the child can't attend at all, or intermittently. It applies to all types of school, free schools, academies, state schools, private schools, and

to children not on roll. It is the LA's responsibility to ensure that all get a 'good' education.

The Department have told me they want the child to know that 'it is not their fault'. They are ill. It is easy for a child to feel a failure when it's the system that is failing them.

There must be no blanket policies for any health condition, nothing inflexible, no lists of what will and won't be done. I recently heard of an LA who drew up a plan for 'CFS' under which every child must attend school. Such plans clearly breach this guideline and should be reported to the Department for Education.

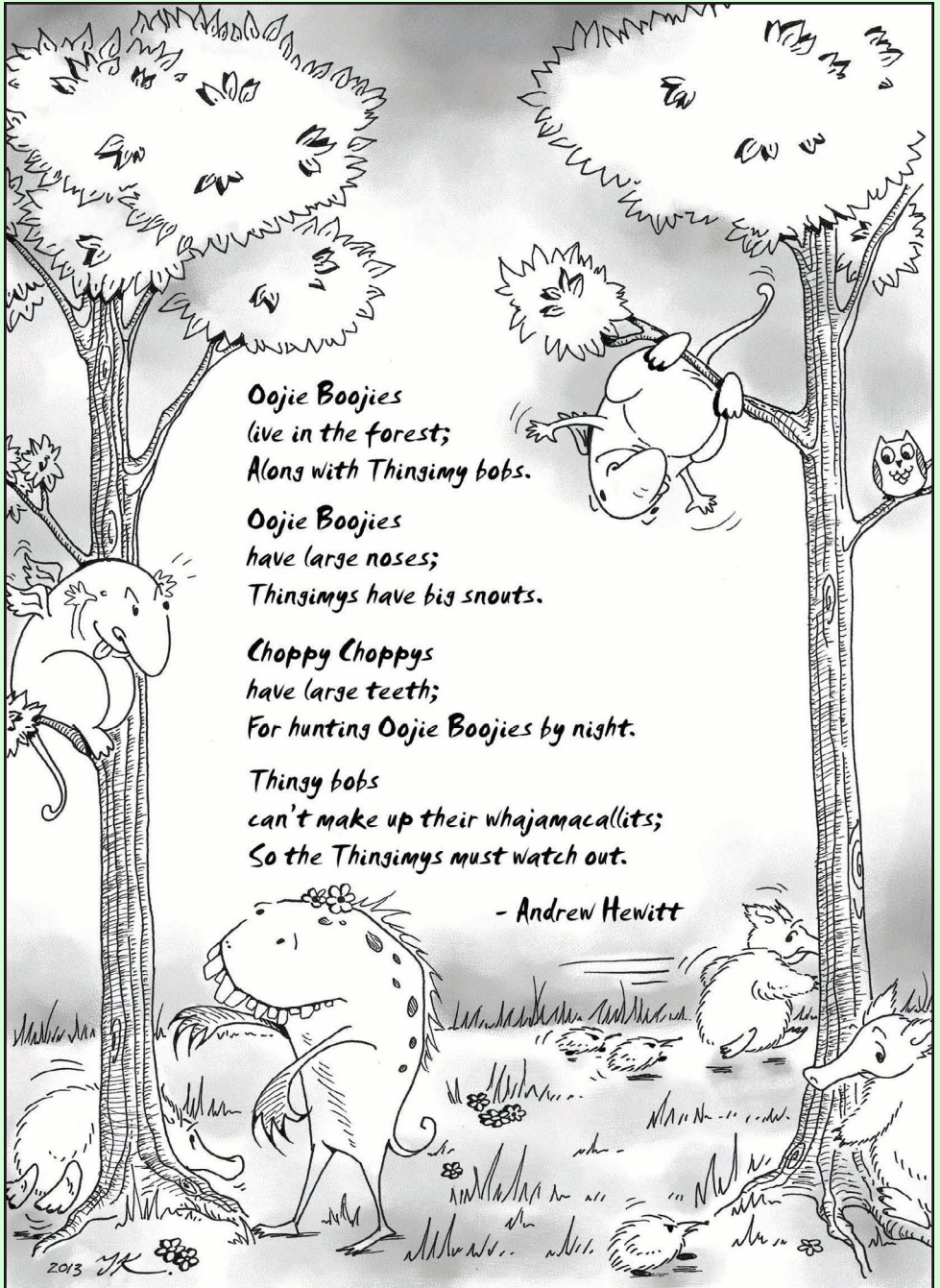
In my webinar I examine the trend for hospitals to prescribe school attendance programmes which schools and tutors feel they must follow, despite families telling us they are a focus for conflict between them and the school. Those I have so far come across run contrary to several aspects of the new statutory guideline. Education professionals must not abdicate their responsibility in their area of

expertise; they become liable if suitable education is not provided.

ME involves disability within the brain, so disability and equality legislation is relevant. Healing takes time, energy and recuperation, and because there is no cure, the National Institute for Clinical Excellence (NICE) states that no treatment need be accepted. Some schools erroneously believe that the family must accept a hospital's management programme, which is clearly contrary to NICE. If it doesn't suit your child, you have the right to say no.

Modern technology and virtual education are successful alternatives or adjuncts to traditional education and I must thank the Nisai Virtual Academy for inviting me to make this presentation and for hosting the live webinar on which it is based.

Find Jane Colby's webinar 2013 statutory guideline on education for children with health needs via www.tymestrust.org.



*Oojie Boojies
live in the forest;
Along with Thingimy bobs.*

*Oojie Boojies
have large noses;
Thingimys have big snouts.*

*Choppy Choppys
have large teeth;
For hunting Oojie Boojies by night.*

*Thingy bobs
can't make up their whajamacallits;
So the Thingimys must watch out.*

- Andrew Hewitt

Illustration by Kathryn from South Africa. Ambition: professional illustrator.



Seb's Awareness Spread

I'm not being left out of this Awareness thing! Young people with ME can and do succeed against the odds. That's my message. IMNSHO they're exceedingly creative, have a great sense of humour and know about getting through tough times. Hang on in there you guys. Big Hugs from me, with all my legs.

Creative Colourings



Joanna Figures



Daniel Scaddan



Alice Gregory



Lynette Connolly's photos

Next door's new pup, and Ulster American Folk Park, Omagh



Should we send your best friend a certificate for their kindness? Contact Us via tymestrust.org.



I am loving my university studies. Only four weeks left and I have finished my first year. God is so good. Never thought I'd be here!!!

Hannah Carling, 26+ Group

Send me the missing rhymes from this poem (one letter for each x) ...

Are the people you know truly ME-aware?

Or do you sometimes feel they just don't xxxx?

Do they text and try to keep in touch?

Or don't they realise it means so xxxx?

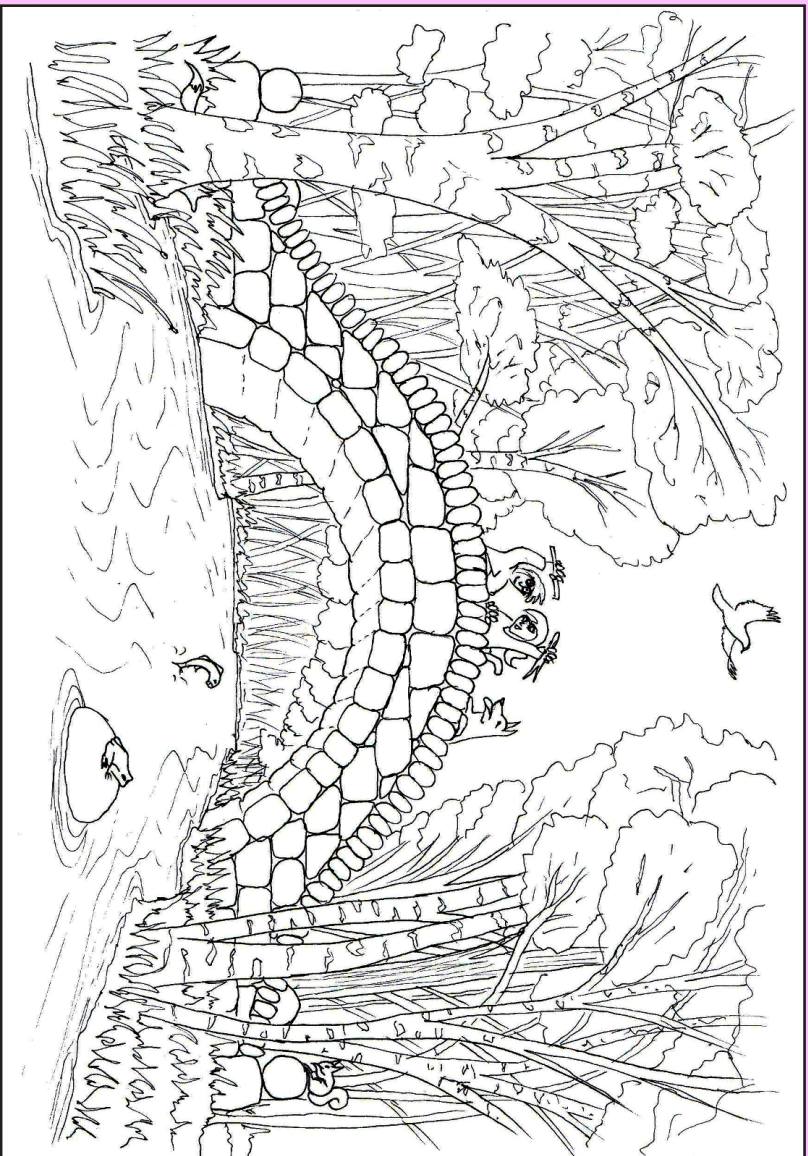
A friend who understands without being told

Is a friend who's worth their weight in xxxx.

... and I'll find you something from my treasure chest!

COLOUR GREGORY'S POOHSTICKS

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!



GREGORY SAYS: CAN YOU SPOT ALL SIX ANIMALS IN THE PICTURE?

PRIZES FOR THE SEVERELY ILL

If you're too ill to colour or count at the moment, tell us what you like about the picture.

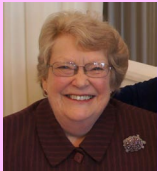
Mum or dad can write or email us for you. The Contact Us form is at tymstrust.org

Name, Age and Address



James Herbert OBE

We were sad to hear of the death of horror writer James Herbert at only 69. Jim, as he let his friends call him, came to a Tymes Trust House of Lords event and amazed us by pulling out his cheque book and donating hundreds of pounds unasked. 'I like what I see,' he said.



The Countess of Mar Shirley Conran OBE

Patrons of Tymes Trust, again sent us generous donations at Christmas which we would like to acknowledge with our grateful thanks.

Selina and Karin

Thank you so much for the lovely soft and cosy blanket which Selina received in the post today. She was very touched, as was I, and she has been using it all afternoon and evening. It means a lot to feel remembered and understood like that, thank you!

Warm wishes,

Karin

We also sent fleeces and throws to other severely ill young people with ME.

From Everyclick: Dave's Movember Moustache Challenge 2012

Target £300, raised £300

Hi everyone, I've been scratching my head trying to work out a fun way to raise funds for the TYMES Trust, a charity that has helped, advised and supported us over the past two years when Tara and then Tasha was diagnosed with CFS/ME and all the challenges that has brought with it. (Tara is

the poster girl for the third TYMES Trust Post-a-Poster Campaign)

The Young ME Sufferers Trust provides families and children with much needed support, information and advice in all areas of life, including valuable printable information documents and leaflets to share with schools, health professionals, friends and family.

Dave Mawer

Dave grew 'the most ridiculous moustache possible'!



Did you know you can set up a free fundraising page for your event at Everyclick? Unlike Just Giving, they don't charge charities for registering.

Have you noticed that donating to charity often just gets you letters asking for more?! **We don't do that.**