

Russell's Report

The Trust is very busy with ME Awareness work this year. I've been designing for them to say thank you for all of the help they gave me when I was ill. I'm now a lot better and working as a graphic designer, my dream job.



Chelmsford in bloom

Chelmsford is the County Town of Essex, just on the Trust's doorstep. It has been granted City status for the Diamond Jubilee. Jane says: 'I took this quick pic on my phone. Can you take one of a place near you? We have lots of prizes waiting.'



Queen's Diamond Jubilee

The Lord Lieutenant of Essex, The High Sheriff of Essex and The Chairman of Essex County Council have invited Jane Colby and a guest to Choral Evensong at Chelmsford Cathedral on Sunday 27 May to celebrate the Diamond Jubilee of Her Majesty Queen Elizabeth II.



Spring at last!

Spring Flowers by Tymes Trust Young Photographer Sarah Coulburt.

Presentation for CAMHS

On Tuesday 22 May Jane will address the CAMHS team at Dunstable at the invitation of Dr Vicky Taylor, Clinical Psychologist. Jane has been asked to present on ME and the work of the Trust.



House of Lords Awards



The Trust is holding an educational awards event at the House of Lords on Monday

14 May, hosted by Founder Patron The Lord Clement-Jones. The Trust works in partnership with the Nisai Virtual Academy so that children who cannot get to school can succeed through interactive virtual education. Government change caused an administrative hiccup in funding for these courses, but after a meeting between ourselves and the Dept for Education, kindly hosted in the Lords by Trust Patron The Countess of Mar, new arrangements are under discussion. Photo: Andrew King receives his Award from Lord Clement-Jones at our last event.

Be part of our new welcome team

All you need is a landline telephone. For details, phone us on 0845 003 9002 or email us on the Contact Us form at www.tymestrust.org



Banned from sleeping

Tara Mawer is featured on Poster 3 in our campaigning series. Children with ME are routinely being stopped from taking daytime naps, despite finding them restorative. The Trust strongly opposes this.

Holidays from home by claire wade



Want something fun to do this summer? To create some great 2012 memories? Come on a virtual holiday to London! Things to do both on and off the computer to help you imagine being there. Fun trivia, quizzes, crafts, recipes, and an exclusive chat area to share your experiences with other virtual travellers.

www.holidaysfromhome.co.uk/shop

Home education success

Susie from our Advice Line says: 'Through following the Trust's advice, my daughter Jade went from trying to do everything at school and achieving nothing ... to achieving really well a step at a time! She is now being home tutored. She is in her third year of 6th form, doing just one subject at a time: History. Before Christmas she covered all she had missed in the first AS year at school, studying for, completing and submitting course work and taking the AS exam. From January onwards she is on course to complete the second part and get a full History A'level. She scored 93% in her History AS and gained 100% in an A2 course work submission. She is even able to have a bit of a social life and is not as isolated as she was going into school and burning out.'

Do treatments for ME/CFS work?

A talk by Jane Colby



You can now watch my talk for the Shropshire ME Group conference. I ask: 'What constitutes treatment? What are we treating? What do

we mean by work? It's actually a very complex question.' My own invention, Graded Growing Therapy, with my adult assistant as a six year-old, causes such hilarity that the camera falls off its mounting. But there is a serious conclusion. Comparing the stages of the illness with recovery from a wound, I show that *when* a treatment is used influences its suitability.

I continue: 'There is something else I haven't mentioned. Is education treatment? We are now seeing paediatricians treating attendance at school as if it were part of a Graded Activity Programme.' I discuss a child's legal right to be suitably educated: 'If all you needed was bums on seats, then all you would have to do if you wanted to go to university is say, "There's my attendance record." Clearly, it's pointless.'

'As a former headteacher myself, I know that children come in all shapes and sizes and abilities and we should celebrate that. And if the child is not well enough to achieve anything at school, because the child is too ill, then why is the child in school?'

I end by discussing how not to be taken in and how to assess a treatment. Is it potentially safe? What does it cost? Is testimony trustworthy? 'Never suspend your own judgement,' I conclude.

Do Treatments for ME/CFS work?

http://www.youtube.com/watch?v=XLnxv_R80KM

Hello Jane

Thank you for this, very much of an eye-opener.
Ute Elliott, Sheffield ME Group

Voices from the Shadows

This film with Professor Leonard Jason, Professor Malcolm Hooper and Dr Nigel Speight shows severe ME and recalls adverse experiences of treatment. Some scenes are harrowing. Producers Natalie Boulton and Josh Biggs warn: 'Some material is distressing and may be considered unsuitable for children.' We agree. But for parents, the story of Child B is salutary (you can jump to that section before seeing the rest). £6 + p&xp at www.voicesfromtheshadowsfilm.co.uk/shop-dvds/

Cruelty to children with ME

In my March email Alert I quoted cruel and unacceptable comments by professionals to children with ME and their families. In return, I received yet more examples.

'I don't care how much pain you're in, you're not going home till lunch time.' (School Head) 'Come back now and we'll forget all this ever happened.' (Deputy Head, who did not inform staff that the child was ill.) 'I once got told that I didn't matter because everyone gets tired.' 'I've been told not to acknowledge my child's symptoms but to "ignore" things and focus on strict "sleep hygiene" routine.' 'School understands that sport should be avoided but insist that pupils spectate.' So the child with ME shivers on the touchline.

An exhausted child, confused after struggling to the surgery, was asked 'if he was he usually this stupid?' Our Advice Line hears that a paediatrician has told a family: 'I don't diagnose ME/CFS. You'll have to go to a mental health specialist.' Another has told a GP that he 'sees lots of these cases, they need pushing or they will stay as they are.'

I'm told that a specialist, denying support for home tuition, declared being 'unaware' of any child not cured by graded activity. Indeed? Another family finds their child's use of her legs deteriorating after exercise treatment by that same clinic. They are naturally angry and have stopped, as have others. One parent reports being expected to commit her daughter to 'specialised' treatment from a physiotherapist without any details. Many feel intimidated; they are told that their child will not recover without treatment, and wrongly informed that home tuition is no longer provided.

I canvass opinion amongst my 'followers': 'To be told to not acknowledge your child's symptoms is appalling! If I had done that, my children's needs wouldn't have been met'; 'That consultant is surely not fit to practise?' One sums it up thus: 'It seems doctors are attempting to terrorise children into getting better.'

'Please help, no one is listening to us,' emails a mum. That says it all. Our third Tymes Trust poster was inspired by cries for understanding from young people with ME. By contrast, it is so affirming to have positive discussions with a GP or a school – kind people wanting to help. 'Two school meetings today were very successful for the parents,' I'm told by our Advice Line Team. 'We have two happy families, very grateful to you for your intervention Jane.' Now that's better.

Posters 1, 2, and 3 www.tymestrust.org

My alert www.tymestrust.org/txt/alert201202cruelcomments.txt

Follow me on Twitter and join the discussion @JaneCColby

