

The Young ME Sufferers Trust

The T Rex In The Room

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An introduction to our 2016 leaflet

Paediatric ME, CFS, SEID for Families and their GPs

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Because I was a GP's wife, I know that GPs need practical ways to help patients where there is no curative treatment. And they also need knowledge of what treatments, or types of management, might be actively *unhelpful*.

Because I was a headteacher, I know how education can be modified for sick children so they can achieve whilst protecting their health and recovery.

And because I got ME (diagnosed by that name) from a coxsackie B virus, I have personal experience. But of course I have also learned a huge amount through working with medical professionals who understand ME. And when I say ME, I do mean, ME. More of that later.

Where there is no curative treatment, GPs need knowledge of what treatments, or types of management, might be actively unhelpful.

The late Dr Alan Franklin was one of the foremost experts in paediatric ME, and it was a real privilege to work with him on the

Chief Medical Officer's Working Group on CFS/ME. This leaflet I'm holding, which we're launching today, has been produced in commemoration of him and his wonderful, compassionate work for children. Everyone respected Alan and he still is sorely missed. Now some of that personal information is in the leaflet. There's a reason for that.

OK, so here was the challenge. One sheet of paper. Why? And what's it all about?

First, the Why. Over my years dealing with - and suffering from - ME, I've worked with some pretty eminent doctors. Dr Elizabeth Dowsett was my first. She was a renowned microbiologist who probably knew more about ME than anyone in the medical *establishment* at that time. She diagnosed me, she demonstrated the cause, through tests - a virus related to polio. She told me that mine was almost the severest case she had ever seen. And she asked me to help her, long before I was really well enough (and she got told off for it by my mum, who was my main carer!) She asked me to help spread knowledge of ME in children, and that was how our schools research began. We discovered that no other illness

causes such long term sickness absence from school. It really is that disabling and Lord Clement-Jones has explained to you one of the reasons for that.

Among the doctors I've worked with, including our guest Dr Charles Shepherd, there was a GP with whom I wrote articles. He called me in to advise the local education authority in a very severe paediatric case of his. He said to me: "Hmm. GPs. Keep it to one sheet!" We've taken his advice.

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What's it all about? Well, we thought it was high time to tackle the Tyrannosaurus Rex in the room - the thorny issue of how ME and CFS are actually not the same thing, and why the present emphasis on fatigue is potentially unsafe for people who would once have been diagnosed with ME - myalgic encephalomyelitis - as originally described by Ramsay - but who now either go undiagnosed



or more likely end up under another illness name such as postviral fatigue or CFS - Chronic Fatigue Syndrome.

That's important because it affects treatment and for children, it affects the type of education recommended too.

I made a typing mistake when I first typed Tyrannosaurus Rex. I put a y in the middle. Tyranny saurus Rex. I thought that was spookily accurate. The fatigue label and the recommendations that have followed from it have become a tyranny. I don't need to tell you how oppressive it is to have your children forced to school when they are not yet well enough, and when there is an excellent replacement in virtual education. The Establishment can

be a bit of a dinosaur when it comes to this type of revolution. There are those who seem to believe that there is some kind of moral virtue in just getting to the school building,

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never mind the educational results. And then I suppose there is the fear: we surely can't buy in a virtual education course for this child - suppose they all want one! But the bottom line is - a child's needs must be catered for. That's the law.

Tymes Trust, whenever it can, sticks to talking about ME. But this is an occasion when it is important to give you one sheet that your GP can see is fully medically referenced, explains how ME, CFS and SEID (systemic exertion intolerance disease - a name suggested by the American Institute of Medicine) relate to each other, and carries medical authority for the information within it.

Of course, doctors, patients, me - author of the leaflet - we're all human. Connecting personally with other people is what it's all about. In the final analysis, GPs want solutions for their patients. We hope this will help.

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