

Notes on talk by Jane Colby, Executive Director of The Young ME Sufferers Trust (Tymes Trust) at Richmond and Kingston ME Group's AGM, 14 September 2013

The main thing to remember about ME is that we cannot make it better (except hopefully with time and rest) but we can make it worse by pushing the child with ME to do things too soon, whether it be Graded Exercise or school attendance.

In 1997 the front page of The Guardian newspaper carried the headline "Schools swept by ME". The study, in which Jane was involved, covered more than 1,000 schools and put ME "on the map".

NICE Guidelines for ME (2007)

Jane was on the children's panel for the Chief Medical Officers Working Group on ME which gave input into these Guidelines, and they did heed some of her advice. She stressed that "education" does not necessarily mean "school" and treatment of any sort (e.g. Cognitive Behavioural Therapy or Graded Exercise Therapy) do not need to be accepted.

However, some medical professionals have misinterpreted this, thinking children should be forced to engage in "treatment". When it is refused, this sometimes results in the professionals placing the child in a "unit" where they are forced to engage in "treatment" while the parents are forbidden from seeing them. This can result in the child's ME being made worse; for instance, going into the unit able to walk and coming out after some time, in a wheelchair, unable to walk.

To date Tymes Trust has been involved in 108 erroneous Child Protection cases in which the child has ME. All of them have been confirmed to be groundless but have subjected the children and their families to huge trauma on top of this terrible illness.

2013 Statutory Guidance for Local Authorities: "Ensuring a good education for children who cannot attend school because of health needs"

Jane has been involved in drawing up this recent guidance. It applies across all types of schools including academies and private schools.

It is important to liaise with the parents and the child and to remember that it is not the child's fault they are ill. The Local Authority and school should not impose inflexible rules.

A letter from a GP is sufficient evidence for the child to start receiving home tuition, it does not have to be from a Consultant. Home tuition can be put in place after a consecutive or cumulative absence of 15 days.

Re-integration plans are not needed from the start of a child's illness (for children with ME re-integration into school can take a very long time). Once the child is strong/well enough, then they can mix education at home with school attendance. One should not necessarily rely on educational programmes "prescribed" by doctors (paediatricians tend to prescribe "graded attendance" at school). Meeting a child's educational needs is responsibility of educators not doctors.

Children with health needs are entitled to be taught in a way that helps them gain qualifications. Attendance at school does not necessarily equate with a "good" or "suitable" education; for children with ME, school can often cause a relapse. Virtual education is particularly suitable for children with ME because it can be done in bits and pieces when the child is able, and it can be used alone.

From misunderstandings about what a child is capable of comeback to not understanding ME, as teachers do not witness the post-exertional exhaustion which often does not kick in until a couple of days after the physical or cognitive exertion at school. The family are the only ones to see this; therefore, they must be listened to.

Jane advises parents to report to the General Medical Council those doctors whose prescribed "treatments" for ME have made a child worse and other health professionals to HealthWatch. They are responsible for safeguarding children.

The most important point is that the individual child's needs should come first and that any "rules" should be flexible.

For further information, go to www.tymestrust.org, click on right of home page: "2013 Statutory Guideline on Education for Children with Health Needs" (Jane's audio presentation with slides; 25 minutes).