



The Young ME Sufferers Trust

ME AWARENESS 2015 : EQUALITY AND ME

Statement by Tymes Trust. Also at www.tymestrust.org/tymespublications.htm.



“The Equality act 2010 sets out the need to treat people equally who have a protected characteristic such as a disability,” wrote Health Minister Earl Howe in 2013. He added: “ME/chronic fatigue syndrome (CFS) falls within the definition of disability.”

Why is this statement from one of our Tymes Trust Patrons so important? There are two main reasons:

- Firstly, it was given in the capacity of a Government Minister and so carries a great deal of weight in asserting that people diagnosed with ME/CFS have a protected characteristic under the Act.
- Secondly, any parent with a child diagnosed with ME/CFS can state that their own child has a protected characteristic, because ME/CFS falls within the Act's definition of disability. We hope this knowledge will assist in avoiding some of the worst pitfalls and misunderstandings that ME/CFS commonly engenders when parents are trying to obtain what their child needs.

As you know, one of the worst misunderstandings that can arise is the suspicion that the parent may be neglecting or harming their child. As a result, the child may be further traumatised by social services investigating their family.

This is not just an occasional case. To date, we at Tymes Trust have advised 142 such families, none of whom have, to our knowledge, been found guilty of anything.

Childhood ME can cause such a degree of illness and disability that it is the biggest cause of long term sickness absence from school. This was first revealed by a five year study, published in May 1997 by the Journal of Chronic Fatigue Syndrome. I carried out this study with microbiologist Dr Elizabeth Dowsett. These children suffer the classic effect of deterioration after effort, which typically occurs over the following few days. They are usually unable to attend school because the physical effort of doing so causes a worsening of their condition, so they need education at home.

Why should this be? Using the Workwell 2-day testing protocol, exercise physiologist Mark Van Ness has shown that the body cannot use oxygen in the normal way. By measuring gases exhaled during effort, he has demonstrated a long suspected impairment in the aerobic energy system. It means that “to try to use aerobic exercise, such as graded exercise therapy, to improve health in these patients” is “utterly counterproductive”. Forcing sick children into school is just another form of exercise, both mental and physical.

Patrons

Lord Clement-Jones CBE, Earl Howe, Lady Elizabeth Anson, The Countess of Mar
Terry Waite CBE, Princess Helena Gagarin Moutafian MBE

John Whittingdale OBE MP, Shirley Conran OBE, Barbara Windsor MBE
The Young ME Sufferers Trust PO Box 4347 Stock Essex CM4 9TE

Telephone: 0845 003 9002 Web: www.tymestrust.org

Registered Charity 1080985



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Despite all these facts, some parents have been threatened with fines and prison for allegedly allowing truancy, and generally disbelieved.

The Equality Act has Technical Guidance for Schools. It states that Protected Characteristics (which Earl Howe has confirmed includes disability by reason of having ME/CFS) establishes a new form of disability discrimination - "discrimination arising from disability". It states: "The Act protects pupils from discrimination and harassment based on 'protected characteristics'".

Under the section "Unfavourable Treatment", paragraph 5.44 states: "For discrimination arising from disability to occur, a disabled pupil must have been treated 'unfavourably'. This means that he or she must be put at a disadvantage. Often, the disadvantage will be obvious and it will be clear that the treatment has been unfavourable, for example being excluded from school. Being denied a choice or excluded from an opportunity is also likely to be unfavourable treatment. **Sometimes, the unfavourable treatment may be less obvious. Even if a school thinks that it is acting in the best interests of a disabled pupil, it may still be treating that pupil unfavourably.**" [Bold added]

Paragraph 5.47 states: "As long as the unfavourable treatment is because of something arising as a consequence of the disability, it will be unlawful unless it can be objectively justified, or unless the school did not know, or could not reasonably have been expected to know, that the pupil was disabled."

Naturally, the matter is complicated. The Technical Guidance gives a relevant example of 'substantial disadvantage':

Example: A pupil with chronic fatigue syndrome finds it harder to concentrate in lessons in the afternoon as a result of an increase in her tiredness. [BOLD added]

In practice, pupils with classic ME can often be better in the afternoon than in the morning. This results from the effects of dysfunction in the hypothalamus gland, which commonly leads to sleep reversal; not only may the child be unable to sleep at night, and need to sleep during much of the morning, but the brain may not be at maximum arousal (and thus more able to concentrate) until the latter part of the day. Whatever the particular disability, if it places the child at a substantial disadvantage "in comparison with non-disabled pupils" then this officially counts as 'substantial disadvantage'.

Children with ME must be given a proper chance to recuperate, convalesce, achieve educationally, and get strong again.

Jane Colby
Executive Director

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