# Why home-based education helps

### Lord Clement-Jones CBE Founder Patron The Young ME Sufferers Trust

### Speaking at the House of Lords

No wonder students with ME find concentration difficult. When the student makes an effort, oxygen levels in the brain can fall instead of rising to cope with the demand<sup>[1]</sup>. Obviously, it can be next to impossible to study effectively after struggling into school.

Research also shows blood abnormalities consistent with a persistent viral infection. Many such facts about ME are not wellknown and this leads to all kinds of misunderstandings. Students can be thought lazy, or just awkward, when they are doing their very best. Often, staff do not realise why the student either can't get to school at all, or can't concentrate on their work when they get there.



## Statement on virtual education

Jane Colby Executive Director The Young ME Sufferers Trust

#### Speaking at the House of Lords

As a former Head Teacher, I was author of the first specialist article on ME in schoolchildren<sup>[2]</sup>. I also co-authored the largest ever study of ME in schools<sup>[3]</sup>. This 5-year survey comprised 1098 schools, 333,024 pupils and 27,327 staff - the largest epidemiological survey of this type made to date. It revealed that ME is the biggest cause of long-term sickness absence from school in both pupils and staff.

Although we have created resources to help with education in-school<sup>[4][5]</sup>, my personal and professional experience and also my research have shown that for young people with ME the most effective form of education is home-based, with interactive virtual education producing grades equivalent to, or higher than, healthy students at school. Social contact is provided by online student groups, and where possible, interaction with the local school.

Such a protocol enables very sick students to achieve, when otherwise they are typically condemned to a recurring pattern of school attendance and subsequent relapse with little to show for it. They often feel they are failures, when in reality it is the educational system that has failed them.

Such a protocol has also been shown to promote the student's health and recovery, in contrast with misguided pressure to get back to school too early in what is a chronic, seriously disabling disease. Pressure of this kind is counterproductive, typically producing



further illness and further interruption to achievement.

Finally, such a protocol is usually far less expensive than traditional home tutoring. It has, over time, not only produced success, but enabled many to get back to school or college again when their physical and intellectual stamina have recovered sufficiently to benefit, with far less detriment to their health.

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[1] Effects of mild exercise on cytokines and cerebral blood flow in chronic fatigue syndrome patients Peterson PK et al Clin. Diagn. Lab. Immunol. 1994, 1(2):222

### [2] The School Child with ME Colby J, British Journal of Special Education Vol 21 No 1 March 1994

- [3] Long Term Sickness Absence due to ME/CFS in UK schools; An epidemiological study with medical and educational implications Dowsett EG, Colby J, Journal of CFS May 1997 vol 3 (2) pp 29-42
- [4] The SENCO's Key Role in Supporting Pupils with CFS/ME http://www.tymestrust.org/pdfs/senco.pdf
- [5] The Tymes Trustcard http://www.tymestrust.org/pdfs/trustcardinfo.pdf

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