

PE1690/AA

Lesley Scott submission of 26 January 2019

The Young ME Sufferers (Tymes) Trust is the only national ME charity dedicated to children and young people with ME and their families. Our entire team work pro bono and in 2010 we received the Queen's Golden Jubilee Award for Voluntary Service, for pursuing the educational rights and advancing the care of children with ME.

I am Tymes Trust Scottish officer and watched with interest the session from the Petitions Committee on Thursday 24th January 2019 that involved Petition PE1690 on Review treatment of people with ME in Scotland.

It was encouraging to see the Cabinet Secretary for Health and Sport and the Chief Medical Officer were both present to answer questions from the Committee on this petition.

Mr Brian Whittle MSP raised the issue of withdrawing GET & CBT from NHS Scotland information and advice as they had been proven to be inappropriate "treatments". Firstly, these are not "treatments", there are no treatments for ME as there is no cure. These are part of what are actually management regimes and there is much evidence to show how harmful particularly GET can be to those with neurological ME. Professor Mark Van Ness has produced some very robust evidence showing the damage that aerobic exercise, which GET is, can have on ME patients. Both the Cabinet Secretary and Chief Medical Officer stated they would not withdraw these "treatments" as they can be helpful for some.

This raises many questions however over what patient cohort is actually helped by such management regimes and whether they do actually have neurological ME in the first place, which makes the criteria on which data is gathered around this patient group very important. The recent Dr Keith Geraghty commentary shows the chaos in the diagnostic procedures for research studies.

https://www.frontiersin.org/articles/10.3389/fped.2018.00435/full?utm_source=F-NTF&utm_medium=EMLX&utm_campaign=PRD_FEOPS_20170000_ARTICLE

But the statements from the Cabinet Secretary and Chief Medical Officer regarding GET & CBT did not address the situation facing many children who have ME and their families.

The Chief Medical Officer stated that

"...the continuance of any kind of treatment, where that person is telling the practitioner that it is not beneficial and is in fact detrimental, why would we continue with that, why would we push somebody in to something that is clearly, from their experience, not right for them?"

Why indeed. Yet for children with ME that is exactly the situation they find themselves in, being told by health professionals to partake in management regimes

that include GET in some form or another or risk being referred to the Children's Reporter.

School attendance is one form of GET that has, in recent years, become very prevalent in how health professionals choose to "treat" neurological ME amongst children and young people. Along with education authorities, health professionals advocate a return to school, gradually increasing attendance without any reference to how this will impact the child's ability to achieve academically but with focus on reintegrating in to peer groups and socialisation. Parents invariably state that the child is not able to attend school and will not be able to benefit from any education offered because all the energy the child has will be used up in actually getting to the school premises or dealing with the noise, sound or cognitive exertion of being in the school.

Yet the response from health professionals and education authorities is to then threaten the child and parents that if the child does not return to school the matter will be referred to the Children's Reporter with parents required to appear before the Children's Panel. This is happening more and more with parents being accused of being "non-engaging" when they will not force their very sick child to attend school and risk relapse to an even greater severity.

Education provision should fit the child, not the other way around.

It is very encouraging to hear that the Scottish Government and the Chief Medical Officer accept and hold to the WHO definition of ME as a neurological disease but the reality for many, including many children and their families, is a frightening draconian process that punishes them for insisting they are severely chronically ill.

The facts given here about what happens to children and their families come from our direct experience of hundreds of families who ask us for help. Families need help to fight against the drive by professionals to return their very sick children to school when they can barely rise from their beds. If the aim is to help, then help them to be given education in a form that has been proven to be beneficial, a virtual education provided online in a safe secure environment in which they can thrive and hold some hope of a future beyond their illness. Help children and young people and their families to stand against the disbelief and misinformation that still colours and drives the decisions of professionals which impact so profoundly on these severely ill children.