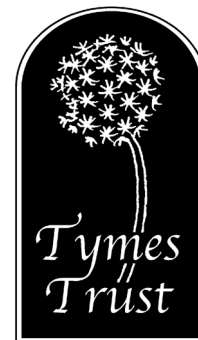


PHYSIOS URGED TO GO CAUTIOUSLY

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by Jane Colby



*Advancing the
care of people
with ME*

I write in response to the advice given by Tina Everett in the article titled "Chronic fatigue syndrome gains more recognition" (*Frontline* November 7, 2001). As a former headteacher, a medical educator specialising in chronic fatigue syndrome/ME and co-author of ME in UK Schools, a 5- year study of a 333,000 school roll with Dr Elizabeth Dowsett [1], I entirely agree with Tina Everett that teachers need more information about this illness in children.

Ninety per cent of parents who contact the national young people's charity Tymes Trust, which I represent on the Chief Medical Officer's Working Group on CFS/ME, report that school attendance is a key cause of relapse. However, Tina's advice on physiotherapy and graded exercise therapy for CFS/ME patients, which might mislead physiotherapists into promoting this treatment for every patient and might also lead teachers to think that children should take part in school PE lessons, is based on the model that these patients suffer deconditioning, a theory now disproved.

A number of abnormalities in muscle function have also been demonstrated, including disturbance of the aerobic/anaerobic systems and abnormal lactic acid build-up. The patient may be able to tolerate exercise at the time, but typical after-effects are exhaustion and renewed symptoms coming on up to 48 hours after treatment and leading to, in some cases, severe relapse. [2]

Doctors have been advised by their medical defence unions that prescriptions for exercise must be given with as much care as those for medication. Surveys by national patient groups have shown that 60% of patients either find graded exercise therapy ineffective, or report that it has caused them harm.

However, the other 40% seem to find it helpful. For physiotherapists, this apparent anomaly makes it difficult to decide on the appropriate treatment for any particular patient. Since chronic fatigue syndrome is thought to be a heterogeneous condition, it is not surprising that some patients, whose illness may not share the same pathology as others', should respond differently. Probably the easiest way to make sure that physiotherapy is appropriate is to go cautiously, remembering the fragility of many of these children, and to bear in mind the stages through which this illness typically passes.

In the first and most severe stage, rest, recuperation and good old-fashioned convalescence are needed. The patient is already likely to be functioning physically at or near their maximum tolerable levels. Active physiotherapy can produce relapse during this stage, whereas gentle passive physiotherapy can be helpful in some cases, to keep blood-flow healthy.

In the next stage, which can take years, during which the illness stabilises and recedes, the patient needs to learn how to

manage their limited energy to promote healing and avoid the “boom and bust” referred to by the Tymes Trust in its courses for professionals and also by Tina Everett.

In the third stage, which is akin to remission (relapse can in some patients be provoked later) more energy output can usually be undertaken, since any setback from doing too much may last only a few days. At this stage, which the patient will probably be able to identify by keeping a diary of activity and its effects, graded exercise therapy is far less likely to be unhelpful and may well assist some people to build up their strength again.

At the 2001 London Day Course on CFS/ME which I ran with the Tymes Trust for the National Association of Educational Inspectors, Advisers and Consultants, medical professionals, educators and parents worked together to determine ways of helping pupils achieve educationally without making their illness

worse. A further course is planned for April 26th 2002 and physiotherapists are welcome.

CFS/ME is centred in the brain and central nervous system and intellectual over-exertion can provoke relapse. Therefore if children are trying to take examinations, any physical activity needs to be reduced until afterwards.

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