

Professional Guides

Physios Urged to Go Cautiously

First published in Physiotherapy Frontline, December 2001

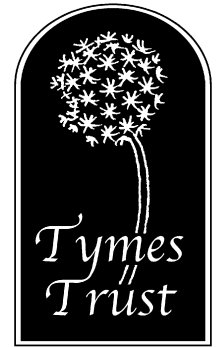
Jane Colby

Former Head Teacher

Executive Director, The Young ME Sufferers Trust

Member, Chief Medical Officer's Working Group on CFS/ME

Member, National Association of Educational Inspectors, Advisers and Consultants



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,

The Young ME Sufferers Trust
Registered Charity 1080985
Patron : Lord Clement-Jones CBE

www.tymestrust.org
Telephone and Fax : 0845 003 9002
PO Box 4347, Stock, Ingatestone CM4 9TE

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.

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.

References

[1] Dowsett EG, Colby J *Long Term Sickness Absence due to ME/CFS in UK schools; An epidemiological study with medical and educational implications* Journal of Chronic Fatigue Syndrome May 1997 vol 3 (2) pp 29-42

[2] Lapp CW *Exercise limits in the chronic fatigue syndrome* American Journal of Medicine 1997 Vol 103 pp 83-84

The Department of Health now refers to this condition as CFS/ME

Many doctors use the term CFS (Chronic Fatigue Syndrome). Others prefer ME (Myalgic Encephalomyelitis) as originated in The Lancet.

This guidance concerns the neurological condition classified under the names ME and CFS by the World Health Organisation as a disease of the brain and nervous system (ICD 10; G93.3).