

Does graded exercise therapy cure ME?

If there were a cure, there would be no controversy. Evidence for this is provided by the large number of severely affected individuals around the UK, most of whom have tried just about every treatment on offer, yet remain severely affected.

In 2007, NICE Guidelines gave qualified approval to Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) due to limited evidence that they might be helpful in mild and convalescent cases. There is no significant evidence that they help severe cases, and plenty

GET is based on the theory that patients have just become unfit (deconditioned)

'If the child doesn't fit the theory then the theory is wrong. In the severely ill, bed rest is not harmful and may be essential [...] Activity levels will naturally increase as the child's symptoms improve [...] Excessive activity can be harmful.'

**The late Dr Alan Franklin
Consultant Paediatrician**

'Papers that disprove the "deconditioning" theory in ME/CFS include (i) Scroop GC et al; Med J Aust 2004;181:578-580; (ii) Schmaling KB et al; J Psychosom Res 2005;58(4):375-381; (iii) Newton JL et al; QJ Med 2007;100:519-526.'

**Professor Malcolm Hooper
Emeritus Professor of
Medicinal Chemistry**

of evidence from the patient community that over-enthusiastic forms of GET can be positively harmful.

The danger of doctors placing too much faith in the efficacy of these forms of management is that, when they fail to work, the doctor may start 'blaming the patient'. They may say: 'this can't be ME/CFS because they are not responding to orthodox treatment' and invoke a psychiatric diagnosis eg Pervasive Refusal Syndrome, abnormal illness behaviour, or Munchausen Syndrome by Proxy / Factitious Induced Illness in children. Alternatively, the family can be blamed for 'sabotaging' the treatment, and their access to the child (if in hospital) restricted.

This well-meaning but in my opinion seriously misguided belief system leads to the family being subjected to the juggernaut of Child Protection proceedings, which in the case of an already severely affected patient amounts to 'Child Abuse by Professionals'.

In the past one felt that once a young person reached 18 they were safe from these pressures but now the same sort of belief system is leading to an adult form of Care Proceedings. Using the Mental Capacity Act, the patient who declines 'treatment' (typically, admission to a psychiatric unit) is said to lack 'capacity' to make their own decisions. The spectre of Munchausen Syndrome by Proxy is invoked to deprive patients of



their liberty on the grounds that they do not understand their own best interests.

Perhaps the next version of NICE Guidelines should state loud and clear:

There is no form of treatment for ME/CFS of such efficacy that it could ever justify a coercive approach.

Once the limitations of GET and CBT are accepted, doctors can recommence their duty to support and care for their patients in a more humane way.

Dr Nigel Speight

Consultant Paediatrician

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

www.tymestrust.org

0845 003 9002

PO Box 4347, Stock, CM4 9TE

