

Time to put the exercise cure to rest?

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There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion 1. And, on follow up over decades (rather than weeks or months), the average person so disabled is found to be functioning (as a student, employee or parent for example) dangerously near their energy limits. The prescription of increasing exercise in such a situation (or in the early stage of the illness when the patient desperately needs rest) can only be counter-productive.

Why do sufferers from ME find energy in such short supply?

Although the brain comprises less than 2% of total body weight it requires 20% of the available body energy and a constant supply of glucose and oxygen to sustain its exceptional metabolic work load. Apart from maintaining sufficient chemical and electrical activity to keep millions of nerve networks constantly charged for action, the brain is a power house which initiates and synchronises all out physiological functions 2. The brain stem and mid brain contain (like the bridge of a ship) all the necessary switches and dials for the passage of information to and from the spinal cord and higher intellectual centres. However, recent research using sophisticated brain scans (PET and SPECT)³ which measures metabolic activity generated during brain functions, have revealed a paradox. Whereas in healthy controls or people suffering from depression metabolism increases with exercise, in patients with ME it is diminished for a considerable period following exercise. Diminished metabolism in the brain stem (which also houses a nerve network, the reticular activating system, charges with keeping us awake and attentive) explains one of the most disabling symptoms of this illness - the unpredictable onset of central nervous systems exhaustion following minor physical or mental activity. Not only are sufferers unfairly assessed for disability benefits by tests (such as the distance walker or the time taken, for example) which take no notice of these prolonged after effects but they are categorised as psychologically disturbed and expected to respond positively to exercise which might only benefit normal people or those suffering from depression.

Do patients With ME suffer from specific muscular problems in addition to general exhaustion?

There are two answers to this question

1) Most patients with M.E. complain of malaise and some experience severe generalised pain. This is related to the disturbance of metabolism in the co-ordinating centres of brain previously described, whereby the appreciation of pain becomes distorted and the supply of natural pain killers (enkephalins and endorphins) diminished. Muscle, joint and bone pain in M.E. may therefore have central origin.

2) Some 30% of patients have a local abnormality in their muscles, when tested for electrical activity (EMG) for the metabolic effects of exercise (the sub anaerobic threshold exercise test) or by biopsy or serological tests (for evidence of persistent or past enterovirus infection) 4. . Whether the individual with M.E. comes into one of these two categories or neither, undue muscular pain or exhaustion following exercise is an indication for rest and some modification of activity. Those who advocate exercise as a cure for M.E. have failed to notice that Nature decrees that we must all spend at least 1/3 of our lives resting in bed. This is necessary for funning repairs to the brain and to damaged muscles or other tissues. Some reparative hormones (eg Growth Hormone) are only produced during this essential period of rest.

What advice can be given about energy management?

There being, as yet, no specific medical treatment that can be recommended for this illness (a statement recently supported by the Department of Health 5.6. despite a contrary view from the Royal College of Physicians that patients for all ages should be offered the 'psychological benefits' of exercise, drugs and psychotherapy), so the first principle of management still remains CONSERVATION OF ENERGY! Being in short supply for all M.E. sufferers, who mainly function in a range of 40%-70% or normal, energy is more valuable than gold dust and must be conserved as such for two essential purposes.

1. To accomplish the essential chores of life, which are not necessarily enjoyable. These can possibly be delegated, made simpler by mechanical means, postponed or omitted if not vital. Why waste this precious commodity?
2. The greater part of any energy available must be reserved for the things most important to you and which you love to do for, without something to look forward to however small, life is not worth living. NB. A great many people love their work, DIY and domestic tasks and for them paragraph (1) will seem like gold dust well spent. For others, even the most housebound, joy can come from a variety of different pets, undiscovered or long forgotten talents (art, writing poetry, music or computer skills) or for occasional outings and carefully planned holidays. Happiness is the finest therapy and will provide distraction even from pain and disability. Postpone ambitions or holiday plans if necessary but never totally relinquish them - life is full of surprises!

Conclusion

Every sufferer from M.E. differs slightly from others in terms of symptoms, life style and stage of illness. No doctor can dictate an activity programme without a clear understanding of the cause and limitations of energy supply in any particular individual and the patient is almost always the best judge of this. It is a good idea to keep a very simple diary to guide the process but don't waste energy on it! Use a few coloured pens and mark on the calendar the percentage of energy (eg 5/10) remaining daily at bedtime. Mark, in other columns, adverse factors (such as visits to the dentist or menstrual periods) saving a big star for pleasurable activities and things to look forward to. If you love athletic pursuits and can't be happy without them, try your own modification but stop before pain and exhaustion set in. Remember that muscles remain constantly in tone if you only move between bed and bathroom and that you can always devise and monitor your own programme at home.

References

DOWSETT, E.G. Rehabilitation in M.E. Tymes 7.8.1997

GREENFIELD, S. The Human Brain - a guided tour. London WIDENFELF & NICHOLSON. 1997

SCHWARTZ, R.B. et al SPECT imaging of the brain: comparison of findings in patients with chronic fatigue syndrome, AIDS, dementia complex and unipolar depression.

SOTERIOU, B et al. Identification of Enteroviral RNA detected in Muscle biopsies from patients with Chronic Fatigue Syndrome or Myositis using reverse transcription-nested pplymerase chain reaction and nucleotide sequencing. Journal of chronic Fatigue Syndrome, 1996; 2(2/3) 74-75.

Letter from FILLIAN MARSH, NHS Executive Headquarters to patient with ME in Leicester, May 1998.

Letter from Baroness Jay, Health Minister to Mr Tim Yeo MP on behalf of a patient with ME in Suffolk, April 1998.