**CONCLUSIONS AND RECOMMENDATIONS FROM THE MEA’S CBT, GET AND PACING REPORT, PUBLISHED IN 2013**

**Cognitive Behavioural Therapy (CBT)**

We conclude that CBT in its current delivered form should not be recommended as a primary intervention for people with ME/CFS.

CBT courses based on the model that abnormal beliefs and behaviours are responsible for maintaining the illness, have no role to play in the management of ME/CFS and increase the risk of symptoms becoming worse. The belief of some CBT practitioners that ME/CFS is a psychological illness was the main factor which led to less symptoms improving, less courses being appropriate to needs, more symptoms becoming worse and more courses being seen as inappropriate.

Our results indicate that graded exercise therapy should form no part of any activity management advice employed in the delivery of CBT, as this also led to a negative impact on outcomes.

There is a clear need for better training among practitioners. The data indicates that lack of knowledge and experience had a direct effect on outcomes and remained a key factor, even where courses were held in specialist clinics or elsewhere given by therapists with an ME/CFS specialism.

However, our results did indicate that, when used appropriately, the practical coping component of CBT can have a positive effect in helping some patients come to terms with their diagnosis and adapt their lives to best accommodate it.

CBT was also seen to have a positive effect in helping some patients deal with comorbid issues – anxiety, depression, stress – which may occur at any time for someone with a long-term disabling illness.

An appropriate model of CBT – one that helps patients learn practical coping skills and/or manage co-morbid issues such as those listed above – could be employed, where appropriate, for ME/CFS as it is for other chronic physical illnesses such as multiple sclerosis, Parkinson’s disease, cancer, heart disease, and arthritis and we recommend all patients should have access to such courses as well as access to follow-up courses and/or consultations as and when required.

**Graded Exercise Therapy (GET)**

We conclude that GET should be withdrawn with immediate effect as a primary intervention for everyone with ME/CFS.

One of the main factors that led to patients reporting that GET was inappropriate was the very nature of GET itself, especially when it was used on the basis that there is no underlying physical cause for their symptoms, and that patients are basically ill because of inactivity and deconditioning.

A significant number of patients had been given advice on exercise and activity management that was judged harmful with symptoms becoming worse or much worse and leading to relapse. And it is worth noting that despite current NICE recommendations, a significant number of severe to very severe patients were recommended GET by practitioners and/or had taken part in GET courses.

The other major factor contributing to worsening symptoms was the incorrect belief held by some practitioners that ME/CFS is a psychological condition leading to erroneous advice that exercise could overcome the illness if only patients would ‘push through’.

We recognise that it is impossible for all treatments for a disease to be free from side-effects, but if GET was a licensed medication, we believe the number of people reporting significant adverse effects would lead to a review of its use by regulatory authorities.

As a physical exercise-based therapy, GET may be of benefit to a sub-group who come under the ME/CFS umbrella and are able to tolerate regular and progressive increases in some form of aerobic activity, irrespective of their symptoms. However, identifying a patient who could come within that sub-group is problematic and not possible at present.

Some patients indicated that they had been on a course which had a gentle approach of graded activity rather than a more robust and structured approach of graded physical exercise. There were some reports that patients were told they should not exercise when they felt too unwell to do so. These led, for some, to an improvement in symptoms or to symptoms remaining unaffected.

However, we conclude that GET cannot be regarded as a safe and effective form of treatment for the majority of people with ME/CFS. The fact that many people, including those who consider themselves severely affected, are being referred to specialist services for an intervention that makes them either worse or much worse is clearly unacceptable and in many cases dangerous.

GET should therefore be withdrawn by NICE and from NHS specialist services as a recommended treatment with immediate effect for everyone who has a diagnosis of ME/CFS. This advice should remain until there are reliable methods for determining which people who come under the ME/CFS umbrella are likely to find that GET is a safe and effective form of management.

**Pacing**

Pacing was consistently shown to be the most effective, safe, acceptable and preferred form of activity management for people with ME/CFS and should therefore be a key component of any illness management programme.

For some, improvement may be a slow process so, whilst they may be somewhat better by the end of a course, the improvement is not enough to take them into a better category of severity for some time, perhaps not until they have self-managed their illness for a few years.

The benefit of Pacing may relate to helping people cope and adapt to their illness rather than contributing to a significant improvement in functional status. Learning coping strategies can help make courses more appropriate to needs even if they do not lead to immediate or even longer term improvement in symptoms. Importantly, it can prevent symptoms from becoming worse.

Pacing can be just as applicable to someone who is severely affected, as to someone who is mildly or moderately affected, although additional measures need to be taken to ensure that a person who is severely affected has equal access to services.

As with CBT, there must be better training for practitioners who are to deliver such management courses. Proposed increases in activity, both mental and physical, must be gradual, flexible and individually tailored to a patient’s ability and circumstance and not progressively increased regardless of how the patient is responding and therapists must be taught to recognise that.

All patients should have access to suitable courses, follow-up courses and/or consultations as and when required.