

GETting worse

Myalgic Encephalomyelitis (ME, or Chronic Fatigue Syndrome, CFS), which affects about 4 per thousand Scots, is a chronic, multi-systemic, inflammatory, primarily neurological disease [1] which is frequently triggered by a viral infection [2]. Post Exertional Malaise (PEM) is a cardinal symptom. Historically there has been some debate as to whether ME is an organic or psychological disorder but the evidence is now overwhelmingly in favour of an organic origin and this is reflected in the Scottish Good Practice Statement [3] (SGPS) as well as WHO [4] and SNOMED [5].

Ironically, the current recommendations for the treatment of ME, advocated by National Health Education Scotland (NES), the SGPS and NICE revolve around two psychological interventions: Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET):

- CBT: to disabuse patients of purportedly “false illness beliefs”.
- GET is a regime of escalating exercise and activity which assumes that feelings of exhaustion and illness caused by the exercise are illusory, temporary and arise from exercise phobia.

This use of CBT/GET arose from the UK MRC PACE trial conducted from 2005 - 2010[6]. PACE reported moderate improvement amongst those who undertook CBT/GET and this became the standard NICE-approved model for ME treatment in England and elsewhere. However, PACE has since been completely discredited:

- “... it will be considered one of the biggest medical scandals of the 21st century.” [7]
- "In short, the PACE study is a sham, with meaningless results.” [8]
- "The PACE trial is a classic case of bad science - researchers are determined to support their theory, even if the data do not." [9]

The scientific evidence for CBT and GET simply does not stand up to scrutiny, whereas the claim by patients that GET is harmful is well supported by the evidence. An independent reanalysis of the PACE (one of several critical reviews of the trial data) concluded "The claim that patients can recover as a result of CBT and GET is not justified by the data, and is highly misleading to clinicians and patients considering these treatments" [10]. There are now numerous papers citing the inevitable long-term harm caused by GET [11, 12, 13]. We don't yet fully understand Post Exertional Malaise but we do know that it's a cellular metabolic disorder with severe and lasting consequences for the patient. Treating ME as a psychological disorder isn't effective. It's not even benign. It's harmful.

It's noteworthy that, due to vigorous campaigning by the scientific and patient community worldwide, the NICE Guidelines for ME, are under review and the final report is expected in October 2020.

What is helpful?

As ME patients we appreciate that our management is difficult and there are relatively few options to be pursued. There are no pharmaceutical treatments aimed specifically at treating the underlying disease. Here are some suggestions:

- Fife is the only region in Scotland to have an ME Specialist Nursing Service where patients are referred when a diagnosis of ME/CFS has been made by the GP. Fife's guidelines for making a diagnosis are based around the Canadian Consensus Criteria [14]; Highland region does not have a service dedicated to ME/CFS.
- The primary management aim should always be to rationalise energy expenditure and respect the limitations of stamina which the patient expresses. Early return to work/education must be avoided

as it is counterproductive;

- We recognise that exercise within what can be comfortably tolerated is beneficial. The amount depends totally on the patient's capacity but could be anything from simply taking a shower to a walk in the country. Anaerobic exercise should be totally avoided;
- Co-morbidities (allergies, IBS, fibromyalgia and depression etc) should be treated thoroughly. Consultation with relevant specialists should be pursued. Bear in mind that patients often have chemical sensitivities and so pharmaceuticals should be introduced slowly and in low doses;
- We recognise that CBT which starts with the correct assumptions about ME can be used to help the patient adjust to their new lifestyle and (often significant) limitations.

Thank you for taking the time to read this.

Written by Stuart Brown and adapted for Highland with permission.

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