

Position Statement on the use of Graded Exercise Therapy (GET) for ME/CFS



4th August 2021

Dear Health Care Provider,

The purpose of this letter is to provide you with evidence-based research into the physiological basis and effective care management of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). The current evidence base dispels the misconceptions that ME/CFS is a psychosomatic disorder in which graded exercise therapy (GET) is a valid treatment. It is our organisation's position that we are concerned about the continued prescription of GET as an intervention/treatment for (ME/CFS).

In the past ME/CFS has been falsely characterised as a medically unexplained syndrome of fatigue that is responsive to talk therapy and GET ^[1]. ME/CFS is in fact a debilitating neurological disease affecting multiple systems in the body. Myalgic Encephalomyelitis has been recognized by the World Health Organization as a neurological disease since 1969 ^[4]. The NICE guidelines for M.E./CFS make no mention of this disease being considered as a functional disorder, thus it should not be treated as such ^[2]. Emeritus Professor Warren Tate and University of Otago researchers have shown unequivocally that ME/CFS are not a psychosomatic illness ^[3].

Many in the medical community have incorrectly asserted that the symptoms of ME/CFS are the result of "deconditioning," "psychological trauma," and/or a "fear of activity" best treated by GET. The hallmark symptom and defining feature of the illness is post-exertional malaise or PEM (Post Exertional Malaise), which describes an immediate or delayed exacerbation of symptoms after mental or physical exertion. Patients experiencing PEM will often describe a relapse after just small amounts of physical exertion causing a further reduction in function and possible increase in illness severity (reference). It can take days, weeks, months or even longer to get back to baseline. ^[5]

Based on PEM it is illogical and paradoxical to prescribe GET to ME/CFS patients. Scientific studies demonstrate that even the mildest of exercise can provoke ME/CFS symptoms ^[6]. In fact, a PEM response can be elicited with such reliability that researchers use exercise to aggravate the illness so it can be studied ^[7].

Misinformation that GET is a treatment protocol for ME/CFS stems from a 2017 Cochrane review ^[8]. However, analysis reveals flaws in the Cochrane review including failure to report harm and conflict of interest, which means that contrary to its findings there is no evidence that GET is safe or effective for treating ME/CFS ^[9]. Up to date evidence shows that GET fails to improve function, is detrimental to the health of the client and should not be recommended as a treatment protocol ^[10].

CCI Support holds the view that it is unethical to treat patients with ME/CFS using this ineffective and potentially harmful "therapy". We believe in listening to patients and paying careful attention to the findings of multiple patient surveys spanning 15 years across multiple countries as reported in the Journal of Health ^[11]. Patients report that GET and CBT have adverse effects and caused a substantial deterioration in their condition ^[12].

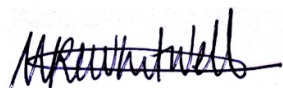
Pacing is the spreading of activities throughout the day and week aiming to try and avoid setbacks by not doing too much too quickly ^[13]. It is our view that Pacing should be used as part of a management plan for CFS/ME patients as is recommended by respected clinical Dr. Rosamund Vallings. Dr. Vallings MNZM, MB BS (Lond), MRCS LRCP, Dip Clin Hyp, BA (Massey) has 35 years in treating patients with ME/CFS. Dr. Vallings has published two books on ME/CFS and is co-author of the IACFS/ME physicians' primer. Dr. Vallings is involved in collaborative research both in NZ and overseas and was awarded Membership of the NZ Order of Merit for services to CFS/ME, plus the Nelson Gantz Outstanding Clinician Award by the IACFS/ME ^[14]. Dr. Rosamund Vallings advises that management should involve very gentle regular activity, whilst avoiding pushing outside the

patient's comfort zone to avoid relapse. Instead, a gradual and cautious increase in exercise by careful pacing is advised [15].

We hope to have drawn your attention to vital information around GET and conclude that GET should not be used in any capacity as a therapeutic treatment for ME/CFS. Please refer to the reference section for further reading.

References

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