

31st January, 2019

NDIS application ME/CFS

We refer to the diagnosis of Myalgic Encephalomyelitis (ME) also known as Chronic Fatigue Syndrome (CFS). The following is a general letter which outlines some of our research and views on ME/CFS. We also provide our views on the utility of Graduated Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) as treatments for ME.

Please be advised that NCNED does not provide specific comments on the research of other researchers and our comments are of a general nature only based on a reasonable appraisal of the state of knowledge in this area.

The illness Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is defined by International Case Criteria (ICC). These criteria are largely symptom-based and no specific diagnostic test currently exists. Our research accepts the basic premise of the validity of the illness as a severely disabling condition in many people with the illness.

Our research work has identified a number of deficits in a group of calcium ion channels known as transient receptor potential (TRP) ion channels. These ion channels enable calcium to enter many cell types in the body, hence likely resulting in or contributing to a multi-system illness.

Our current work continues to identify genetic and other associations with the illness and this has been validated in a number of cohorts under investigation.

We do not support so-called Graduated Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) as treatments for ME. Our reasons are that calcium ions are essential for the normal functioning of many body systems. Impaired TRP channels result in impaired entry of calcium ions into the cells thus impeding function.

Collectively these symptoms present as the illness known as ME/CFS. Indeed exercise is now widely thought to exacerbate patients' deteriorated physical condition. Cognitive Behavioural Therapy is not thought to influence calcium ion function, and also for other reasons, is therefore not seen to be of benefit.

On the balance of evidence CBT and GET should not be continued as treatments for CFS/ME and may even be harmful. Hence their use cannot be supported.

A review of literature recently published by us shows no evidence-based treatments are convincingly effective in CFS/ME currently.

Kind regards,

Two handwritten signatures in black ink. The signature on the left is stylized and appears to be 'S.M.G.' or similar. The signature on the right is more cursive and appears to be 'D. Staines'.

Professor Sonya Marshall-Gradisnik & Professor Donald Staines
Co-Directors
National Centre for Neuroimmunology and Emerging Diseases
Menzies Health Institute Queensland (MenziesHIQ)
Griffith University
Gold Coast Campus