



Position Paper
on the management of
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome
(ME/CFS)

October 2020

The British Association for CFS/ME (BACME) is a multidisciplinary organisation for UK professionals who are involved in the delivery of clinically effective services for patients with ME/CFS.

Our Mission is to support health care professionals to develop and deliver clinically effective and holistically informed practice for children, young people and adults with ME/CFS and primary fatigue conditions.

ME/CFS is a serious and complex chronic multi system illness that can profoundly affect the lives of people who develop it.

BACME fully supports research into the biological causes and mechanisms of the illness.

There is evolving evidence to indicate a dysregulation of multiple dynamic physiological systems in explaining the symptom picture seen in ME/CFS. Research has demonstrated changes in Immune System responses, Autonomic Nervous System function, Neuroendocrine pathways including the Hypothalamus-Pituitary-Adrenal axis along with cellular metabolic changes.

BACME supports clinicians to underpin rehabilitative and therapeutic processes with a grounding in dysregulation principles.

BACME does not support the deconditioning model of ME/CFS as a primary cause for the condition. It is recognised that deconditioning may be, for some, an additional complicating factor of living with any disabling chronic health condition.

BACME believes that patients should have access to the best available clinically effective treatments, therapy and support with rehabilitation to relieve, reduce and manage symptoms where possible. This will allow patients to make informed choices as to how to manage the impact of ME/CFS on their quality of life and optimise the potential for recovery.

The World Health Organisation defines Rehabilitation as a “process aimed at enabling people to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides people with the tools they need to attain independence and self-determination. Rehabilitation is concerned not only with physical recovery, but also with psychological and social recovery and reintegration (or integration) of the person into the community.”

BACME supports the delivery of flexible, person specific programmes that take into account the underlying biological processes.

BACME supports grading activity strategies when delivered by an ME/CFS specialist clinician to make increases and improvements in physical, cognitive and emotional function from an identified stable baseline. BACME does not support inflexible Graded Exercise Therapy (GET) built on a primary deconditioning model. A deconditioning based approach would involve an inflexible, structured approach where regular increases in activity are encouraged regardless of how the patient is responding.

BACME supports the use of Cognitive Behavioural Therapy (CBT) strategies and other psychological interventions with the aim of developing management strategies delivered by a specialist ME/CFS clinician who has a good understanding of ME/CFS. BACME does not support the use of inflexible CBT programmes delivered by practitioners who do not have a good understanding of the biological aspects of ME/CFS.

Rehabilitation is to be appropriately tailored to an individual's needs and personal goals and provided within a holistic model. A flexible framework of monitoring and review is recommended and is best achieved by providing continuity of care.

We support the continuing development of specialist multi-disciplinary ME/CFS services and specialist clinicians to guide, support and advise patients towards optimal health, wellbeing, and recovery. This is a complex illness but given prompt specialised intervention we expect improved quality of life, understanding of living with the illness, and progress for each patient.

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