25% M.E. Group
Support for Severe M.E.

https://25megroup.org/about-us

Email: enquiry@25megroup.org
21 Church St, Troon,
Ayrshire. KA10 6HT

5th November 2020

Dear BACS Members

British Association for CFS/ME Position Statement October 2020

We are 25% ME Group charity, the only charity concerned specifically with the needs of the severely affected. Being formed over 25 years ago, we have a wealth of experience and as such are generally seen as an authority on Severe ME, we are active in campaigning for better diagnosis, treatment and care of people with Severe ME, for example being a stakeholder in the NICE review, supporting use of ICC, undertaking surveys about various aspects of Severe ME, disseminating information, etc, and we are a respected voice for people who are the most affected by ME

We have read your October 2020 Position Paper and some of our members have asked us to write to you for clarification on the following points:

1. Does your abandonment of the deconditioning model mean you do not support the cognitive behavioural model of ME - otherwise known as the BPS model.
2. Do you still support the use of CBT as a primary intervention? Do you believe CBT that does not overlap with pacing reduces physical symptoms?
3. Since abandoning the deconditioning theory, can you say whether "fear of exercise / activity" is no longer to be considered an "unhelpful" belief related to the illness and would no longer be challenged?
4. Can you outline exactly which thoughts and behaviours CBT for ME are examples that occur in ME Patients? What are the typical "illness beliefs" addressed in the cognitive side? Which "illness behaviours" will be addressed?
5. Can you explain what illness thoughts are linked to the "demonstrated changes in Immune System responses, Autonomic Nervous System function, Neuroendocrine pathways including the Hypothalamus-Pituitary-Adrenal axis along with cellular metabolic changes" that your statement refers to.
7. Do you believe that the illness is partially psychological and partially physical, or do you accept it is entirely physical given the World Health Organisation classification, and the absence of any psychological symptoms in any of the current diagnostic criteria (old NICE, CSC, Fukuda, etc)?
By “physical only” this means that there is an absence of common psychological processes or symptoms, other than reactive depression / anxiety, and is no more psychological than other neurological illnesses. (Bearing in mind that some neurological diseases have a few primary psychological symptoms).

8. If you believe it is physical only when and how will you be informing your members of this? You have previously held this view.
9. We wonder why your statement about ME/CFS when the organisation name is CFS/ME? Are you planning to change your name?
10. Do you accept that ME has an underlying disease process, which has directly caused the deaths of some patients?
11. How and when will you be updating their guide for severe ME?

We look forward to hearing from you and we will share your response with our members

Regards

Simon Lawrence
Chair person