

**Action for M.E. summary of the National Institute for Health Excellence (NICE) guideline for M.E./CFS, draft for consultation, November 2020**

**Section 1.11 Managing ME/CFS**

**Key messages for this section**

- The guideline is clear that graded exercise therapy (GET) should not be offered: “Do not offer people with ME/CFS any therapy based on physical activity or exercise as a treatment or cure for ME/CFS.”
- Psychological support, such as cognitive behaviour therapy (CBT), may be used to reduce distress and support patients to develop coping skills but NOT a treatment or cure for M.E.
- It should not be assumed that deconditioning is the cause of M.E., nor that people with M.E. have ‘abnormal’ illness beliefs and behaviours as an underlying cause.
- Patients should be given information about the risks and benefits associated with physical activity, including that some people with ME/CFS have found that physical activity programmes can make their symptoms worsen, for some people it makes no difference and others find them helpful.
- Patients should be offered support with energy management, to help prevent worsening of symptoms. Activity should be reduced, not “pushed through,” if it is having a negative effect. Activity should only ever be increased if led by the patient.
- Advice should be shared about the important role resting plays in managing M.E., and that “rest periods are part of all management strategies for ME/CFS.”
- Patients should be given advice, as needed, on managing sleep, orthostatic intolerance, pain, nausea and diet, with attention paid to the lack of evidence to support routinely taking vitamin and mineral supplements.
- The guideline advises not to offer “any medicines or supplements to treat or cure ME/CFS.”

**Further details**

The guideline is clear that “there is no current treatment or cure (non-pharmacological or pharmacological) for ME/CFS.”

The word pacing is not used. Instead, the guideline refers to “energy management” with clear advice that this is to support living with symptoms, and not a cure.

It says that this self-management strategy:

- can be applied to any type of activity
- helps people understand their energy envelope so they can reduce the risk of overexertion worsening their symptoms
- recognises that each person has a different and fluctuating energy limit, and they are the best judge of their own limits
- can include help from a healthcare professional if needed

- uses a flexible, tailored approach so that activity is never automatically increased but is progressed during periods when symptoms are improved and allows for the need to pull back when symptoms are worse.

The guideline advises that patients/carers be given support on how to recognise and prevent possible impact of being able to move very little or not at all, eg. pressure ulcers, deep vein thrombosis.

The advice given about physical activity is clear that it should not be used with the aim of treating or curing people with M.E.

The guideline also says that people with M.E. should not be offered “any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy.”

Instead, if a patient chooses, it may be used when they are “ready to progress their physical activity beyond their current activities of daily living, or would like to incorporate physical activity into the management of their ME/CFS.” Support from an experienced professional should be sought.

The guideline clearly sets out the components that an appropriate programme of physical activity include, such as establishing a manageable baseline of physical activity, and successfully maintaining this before choosing to increase activity.

Cognitive behaviour therapy (CBT) is suggested only in the context of psychological support; not other type of counselling or psychological therapy is mentioned.

The guideline is clear that CBT may “reduce the psychological distress associated with having a chronic illness. Do not offer CBT as a treatment or cure for ME/CFS.”

As with physical activity above, it clearly sets out the components that supportive CBT should include, such as a shared understanding of the challenges faced by the person with M.E., an exploration of what the symptoms and illness mean to them, and strategies that they find helpful.

**For more information about the NICE guideline for M.E. or to share your view, please visit [www.actionforme.org.uk/NICE](http://www.actionforme.org.uk/NICE)**