

Science Media Centre Factsheet

CFS/ME – The illness and the controversy

Chronic fatigue syndrome (CFS), also known as myalgic encephalopathy or myalgic encephalomyelitis (ME), refers to an illness of uncertain cause for which the main symptom is long-term debilitating fatigue that is disabling and not relieved by rest.

CFS/ME is highly controversial with longstanding disagreements between the mainstream medical community and campaigners about its cause and treatment.

The Illness

What is it?

- CFS/ME is a severe, chronic illness characterised by long term physical and mental fatigue, that can occur after minimal exertion and interferes with daily life. It can also include symptoms such as difficulty sleeping, muscle/joint pain, headaches, cognitive dysfunction, general malaise or flu-like symptoms.
- According to the National Institute for Health and Care Excellence (NICE), the diagnosis should only be made if fatigue, along with other symptoms, has persisted for at least four months (three months in children). There is currently no validated biomarker or test for CFS/ME, and a diagnosis is usually given based on symptoms after all other causes of the fatigue have been excluded. The international scientific community has not agreed on a single definition of the illness although most proposed definitions are similar. CFS/ME affects around 0.75% (with a range of 0.23–1.29%) of the UK population. Adolescents and adults alike can be affected with women more likely to be sufferers than men
- After developing CFS/ME some people may regain full health and live active lives, while others will suffer relapses or remain severely affected. Some patients are able to maintain jobs while a minority become house or bed-bound.

What causes it?

- Various causes have been proposed and investigated, including infectious, immunological, metabolic, and psychological factors; all appear to play a role in some cases but no single major cause has been identified.
- Physiological differences between healthy individuals and individuals with CFS/ME have been observed, such as differing cytokine levels. However it has not been proved that these differences are a causal factor in the condition.
- Some scientists think CFS/ME will prove to be a number of separate illnesses with a variety of causes.

What can currently be done to treat it?

- There is presently no cure for CFS/ME, but rehabilitative therapies, Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are currently recommended by NICE. These therapies can be tailored to the severity of the illness and have been shown to help patients with mild to moderate CFS/ME
- CBT is a talking therapy that helps patients to work out how best to understand and manage their illness, with the aim of enabling them to do more of the things they want to do. Typically patients start by becoming more consistent in the way they approach activity and then build up

activities slowly over time. CBT can also help patients to improve their sleeping pattern. Some evidence suggests that CBT can have subsequent physiological effects such as reducing levels of the stress hormone cortisol. CBT is used in a variety of other conditions such as anxiety disorders, insomnia, chronic pain, inflammatory disorders and neurological conditions

- GET is a structured exercise programme that helps the patient to establish a comfortable and stable level of physical activity before trying out gradually increasing activity in a consistent and carefully monitored way. GET also aims to help patients to gradually do more of the activities that they value. It can also be used to aid recovery from other illnesses such as heart disease and cancer
- Medical care also has a role in helping patients to manage other symptoms such as pain
- Based on evidence from numerous studies and clinical trials, CBT and GET, when given as supplements to medical care are considered the best currently available treatments. They offer an overall moderate benefit in reducing fatigue and increasing activity, with some patients benefitting more than others. The trials also show that CBT and GET are safe, when delivered appropriately by trained practitioners
- Other proposed treatments such as 'pacing', which for most people is the same as activity management but can be done in lots of different ways, are not supported by evidence as effective treatments, despite some patients preferring this approach. NICE states 'there is insufficient research evidence on the benefits or harm of pacing'

The Controversy

What is the controversy?

- Amongst the mainstream medical research community, CFS/ME and NICE recommended management is not especially controversial. Likewise, data from centres specialising in CFS/ME report good patient outcomes and satisfaction. However the management is highly controversial among a minority of patients and doctors. A major point of contention is whether psychological and/or behavioural factors play any role in the illness, and likewise whether psychological and behavioural therapies have anything to offer as treatments.
- One reason behind the controversy, which is long standing, is a concern that recommending these sorts of therapies means that the illness is 'all in the head' and not a 'real illness'. This view dates back to previously pejorative media coverage (such as describing it as 'yuppie flu') and a perceived lack of recognition by doctors and others that CFS/ME is a serious illness
- Some people do not accept that psychological factors play a role in the illness or its treatment and dispute many aspects of the evidence that supports CBT and GET as treatments. Some also claim that these treatment are harmful. A minority have engaged in activities designed to actively disrupt such research.
- Doctors and scientists have repeatedly emphasised that the use of CBT or GET as treatments does not indicate that an illness is purely 'psychological' in nature and that the oft-repeated but unhelpful dichotomisation of illness into either psychological or physical is neither scientifically valid nor clinically useful. The scientific evidence increasingly renders medical boundaries between body and mind as obsolete.
- The existing evidence for CBT and GET for CFS/ME, cited by the scientific community and underpinning NICE recommendations, consists of approximately a dozen randomised controlled trials and meta-analyses published in journals like *The Lancet* and *PLoS*, and three Cochrane reviews (generally considered the gold standard of medical evidence). Those who disagree with this body of evidence cite review articles and reanalyses of trial data published in low impact factor journals such as *The Journal of Health Psychology* and *Fatigue: Biomedicine, Health & Behavior*
- The current NICE guidance were published in 2007 based on evidence available at that time. Subsequent clinical trials and reviews have continued to support the recommendation that CBT and GET should be offered for people with mild or moderate CFS/ME. NICE reviews all of its guidance periodically. In the summer of 2017 NICE stated that there was not sufficient new

evidence to warrant reassessing its guidance, but after a public consultation on this stance received extensive feedback from patient groups, NICE is now reviewing whether its recommendations need to be changed. The results of this review are expected in 2020. After sustained pressure from activists the CDC has removed mention of CBT and GET from its website and currently states that there is no approved treatment for CFS/ME despite evidence to the contrary.

The evidence

- Among the evidence base for the use of CBT and GET for CFS/ME, the trial that attracts the most controversy is the PACE Trial funded by the UK Medical Research Council (with small amounts of additional funding from the Department of Health, Department of Work and Pensions and the Scottish Chief Scientist Office). It aimed to compare the efficacy of CBT, GET, and Pacing as supplements to medical care and medical care alone. Its main findings were published in *The Lancet* in 2011 and its findings were consistent with previous evidence that CBT and GET were moderately effective and safe treatments for CFS/ME patients. It found that on average these treatments improved patients illness more than the other treatments tested; some individual patients improved a great deal and others not at all. It also found that pacing was not effective. These findings were well received by most clinicians but not by some activists.
- Critics of the trial have claimed that it was poorly designed. However, experts from the medical community, including independent statisticians, trial design specialists, and other researchers have stated that it is a good quality trial albeit with unavoidable limitations reported in the paper. The trial was included in Cochrane Reviews of the evidence-base.
- Other trials that have attracted similar criticism include a number of trials conducted in the Netherlands, the on-going MAGENTA trial in the UK, the recently launched FITNET-NHS trial in the UK and recently published SMILE trial. These are all trials investigating whether forms of CBT, GET or other behavioural therapies can help patients with CFS/ME
- Whilst CBT and GET are the best currently available treatments, CFS/ME clinicians, researchers, and patient groups all agree that more funding and more high quality research is needed to better understand the causes and mechanisms involved in the illness if we are to develop more and better treatments

Sources / further information

[NHS Choices - Chronic fatigue syndrome \(includes descriptions of CBT and GET\)](#)

[NICE CFS/ME guidelines](#)

[QMUL Pace trial FAQs](#)

[Price, JR *et al.* \(2008\) "Cognitive behaviour therapy for chronic fatigue syndrome in adults", Cochrane Library](#)

[Malouff, JM *et al.* \(2008\) "Efficacy of cognitive behavioral therapy for chronic fatigue syndrome: a meta-analysis." Clinical Psychology Review, Jun, 28\(5\): 736-45](#)

[Castell, BD *et al.* \(2011\) "Cognitive Behavioral Therapy and Graded Exercise for Chronic Fatigue Syndrome: A Meta-Analysis" Clinical Psychology, Vol 18, Iss 4 p311-324](#)

[White, P *et al.* \(2011\) "Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome \(PACE\): a randomised trial" Lancet Vol 377, Iss 9768, p823-836](#)

[Marques, MM *et al.* \(2015\) "Differential effects of behavioral interventions with a graded physical activity component in patients suffering from Chronic Fatigue \(Syndrome\): An updated systematic review and meta-analysis" Clinical Psychology Review, Vol 40, p123-137](#)

[Vos-Vromans DCWM *et al.* \(2015\) "Multidisciplinary rehabilitation treatment versus cognitive behavioural therapy for patients with chronic fatigue syndrome: a randomized controlled trial" Journal of Internal Medicine, Vol 279, Iss 3, p268-282](#)

[Larun *et al.* \(2017\) "Exercise therapy for chronic fatigue syndrome" Cochrane Library, Database of Systematic Reviews](#)

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