

Myalgic Encephalomyelitis (ME)

Parliamentary Briefing

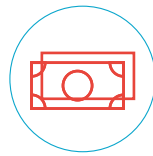


OVERVIEW

*Myalgic encephalomyelitis (ME) is a **chronic, debilitating, multi-system disease** that affects approximately 250,000 men, women and children of all ethnicities, ages, and genders in the UK*



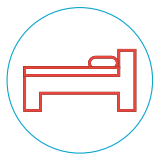
ME is twice as common as MS



The economic cost of ME in the UK is at least £3.3 billion per year



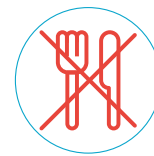
95% of people with ME do not recover



25% of patients are housebound or bed-bound due to ME



Median quality of life for people with ME is worse than chronic renal failure and cancer



Severe patients have extreme sensory sensitivity and may need to be tube-fed



Children as young as five years old may develop ME



ME is the most common cause of long-term school sickness absence



Many remain sick and disabled for the rest of their lives

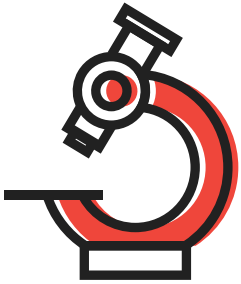
AND YET

- + The UK government does not fund research and clinical care for people with ME at the rate of other serious, prevalent diseases. Increased funding of biomedical research after decades of under-investment is urgently required.
- + We must take immediate action to end the use of CBT and GET as treatments for ME. These debunked treatments are ineffective, potentially harmful, and contribute to an environment of disbelief and neglect.
- + We must endorse updated training for healthcare professionals to reflect international consensus on best practice.
- + We must ensure that families of children with ME are not subjected to unjustified child protection procedures. This is often related to a lack of understanding of ME and how it affects a child's ability to attend school.

Please attend and vote in the parliamentary debate to improve the lives of your constituents with ME!

Fund biomedical research for ME at equitable levels

ME receives far less research funding than other neurological conditions of similar prevalence or disease burden. People with ME are “measurably more disabled” than those with multiple sclerosis (MS), which is estimated to be half as prevalent as ME in the UK.¹ And yet, MS receives at least 20 times more research funding than ME.²



The WHO classifies ME as a neurological condition. Global scientific consensus is that investigating, treating and curing ME requires a significant investment in biomedical research³. However, the vast majority of UK public funding for research into ME has been awarded to psychological and behavioural studies⁴, which have left people with ME mistreated, neglected and abused.⁵ It has also resulted in the NHS IAPT (Improving Access to Psychological Therapies Programme) erroneously listing ME as MUS (Medically Unexplained Symptoms).⁶

The only year that the MRC (Medical Research Council) invested any meaningful sum in biomedical ME research was in 2012 when £1.5m of funds were ring-fenced, with a resulting investment of £1.6m. However, no funds have been allocated for biomedical ME research since then.

Funding for research must reflect the severity of ME and its prevalence throughout the UK. The ME community experiences a considerable disease burden, and for decades has faced underinvestment, mistreatment and neglect. The need for biomedical ME research is urgent and long overdue.

Stop GET and CBT

Cognitive behavioural therapy (CBT) and graded exercise therapy (GET) are currently first-line treatments for ME in the UK. However, studies show that CBT is ineffective, and patient surveys with thousands of total respondents show that GET is harmful for people with ME. The NICE guidelines recommending these treatments for people with ME are currently under review.

In addition, the US Agency for Healthcare Research and Quality (AHRQ) has downgraded their recommendation of GET and CBT in ME, and the Centers for Disease Control and Prevention (CDC) has removed these treatment recommendations from its website. The PACE trial, the flagship study of GET and CBT for people with ME [has been debunked](#)⁷. It has been flagged with a letter of concern by PLoS One (the Public Library of Science) and multiple critiques of the study's flaws have been released by academics and MPs. The PACE trial has been used in academic coursework as an example of poor study design and unethical reporting practice.⁸ Researchers all over the world are still calling for its retraction.



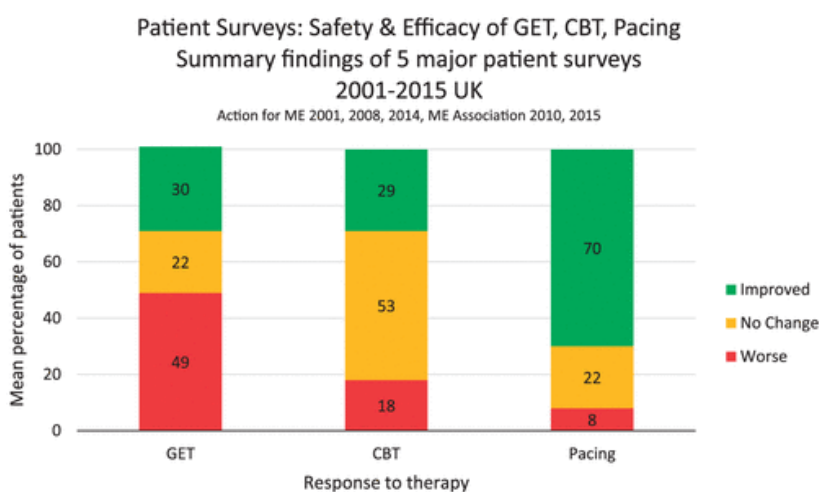
GET is a form of physical therapy for ME in which physical activity is gradually increased over time. GET may be helpful in other diseases and disorders. However, metabolic changes in ME may make overexertion harmful. The following changes have been measured in people with ME **during exercise**.

People with ME	Healthy People
Reduced blood flow to the brain and heart ⁹	Increased blood flow to the brain and heart
Reduced oxygen uptake in red blood cells ¹⁰	Increased oxygen uptake in red blood cells
Reduced oxygen utilisation ¹¹	Increased oxygen utilisation

A 2018 survey with over 600 respondents¹² found that most ME sufferers (89%) experienced worsened symptoms after increasing activity. Very few (5%) reported that increasing activity or exercise helped them feel better. Physician-led GET was also found to increase symptoms in the majority of people with ME in a 2015 survey.¹³

CBT is a talking therapy which focuses on challenging and changing unhelpful thinking patterns, cognitive distortions and resulting behaviours. It is commonly used in relation to mental health. There is also an appropriate role for talking therapy in chronic illness in order to adjust to a difficult change in circumstances. However:

- + When CBT is applied to chronic illnesses, it is usually to complement biomedical treatment, not to replace it.
- + The CBT typically used in ME presumes that the underlying physical illness can be treated by cognitive and behavioural changes. This does not match the international consensus on the biomedical nature of ME.
- + CBT is not an effective treatment for ME. Though some studies report better outcomes with CBT using patient surveys, these subjective effects are shown to wear off over time, and objective measures – like actimeters/step-trackers, getting off benefits, and going back to work – are unaltered, or may even be worse after CBT.¹⁴



- + Significant results are from studies that rely on subjective questionnaire outcomes. This is particularly problematic in an intervention aimed at changing thought processes and behaviours. These subjective effects diminish or disappear by long term follow up.

[This graph](#) illustrates the impact of CBT and GET on ME symptoms. Note that pacing – alternating periods of activity with periods of

rest – is shown to be most likely to improve symptoms. It differs from GET as patients listen to their own bodies. GET is associated with worse symptoms in an overwhelming majority of people with ME, while CBT shows no effect in most.¹⁵

There is no cure for ME. However, there are treatments and management techniques that can significantly improve patients' quality of life, such as pacing, and relatively inexpensive testing that can point to helpful clinical action. CBT and GET are far from the only choice for people with ME and their clinicians.

Provide updated professional training on ME

There's an urgent need to update the training of GPs and other healthcare professionals so they are equipped to diagnose ME, offer appropriate management advice, and provide palliative treatments that reflect the international consensus on best practices. Early diagnosis and proper management are vital, as this may prevent deterioration and present the best chance of long-term improvement. GPs currently use the NICE guidelines for ME, but these guidelines are under review, and contain outdated and potentially harmful information.

During the 2018 Royal College of General Practitioners (RCGP) Conference, a workshop on ME was oversubscribed, with over 250 GPs in attendance.¹⁶ Timely, contemporary, continuing medical education for ME should be ensured by the Chief Medical Officer and Department of Health and Social Care.

ME is a complex, often lifelong illness, but the caring support of medical professionals makes an enormous difference in the lives of patients. Clinicians must have access to contemporary information on ME in order to provide the best possible care.

Support children with ME

ME is estimated to affect **25,000 children in the UK**¹⁷, and is said to be the **leading cause of long-term school sickness absence** in the UK.¹⁸ Too often schools do not make the necessary adjustments that could enable children to continue with their education either part-time or by completing tasks at home.

If the carer of a young person with ME declines to put their child through a course of CBT or GET, families report that they are at greater risk for child protection referrals. Families are referred to safeguarding by clinicians when the child doesn't recover or gets worse; or by schools due to low attendance. A 2017 study found that more than one in five families caring for a child with ME have been referred for child protection proceedings. The vast majority of these accusations are dismissed in less than a year, as they are based on school absences coupled with misunderstanding the nature of the illness.¹⁹

The focus on rehabilitation in clinics that rely on CBT and GET -- treatments shown to lead to no objective gains in function in people with ME²⁰ -- set children up to fail. It's unconscionable, selling children and their families this lie, built on bad science: that young people can improve if they work hard and have enough faith in the process.

Given the stigma people with ME face, families will continue to meet accusations of misconduct and withholding of support. Without direct and decisive action, the mistreatment faced by children and families will continue on its established course. Families of children with ME face and overcome enormous challenges every day, both medically and educationally, due to widespread ignorance and a lack of effective treatment.

The only way to eradicate these issues is greater investment in biomedical research, and greater education for clinicians, medical staff, professionals and social workers.

ENDNOTES

¹ Kingdon CC. (2018), Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls. *Pharmacoeconomics Open*. <https://doi.org/10.1007/s41669-018-0071-6>

Komaroff AL et al. (1996), Health status in patients with chronic fatigue syndrome and in general population and disease comparison groups. *Am J Med*; 101: 281–90. [https://doi.org/10.1016/S0002-9343\(96\)00174-X](https://doi.org/10.1016/S0002-9343(96)00174-X)

² Chowdhury S et al. (2016), ME/CFS Research funding. An overview of activity by major research funders included on the dimensions database: <http://www.mereseearch.org.uk/wp-content/uploads/2016/09/mecfs-research-funding-report-2016-final.pdf>

³ Institute of Medicine (2015), Beyond myalgic encephalomyelitis/chronic fatigue syndrome: redefining an illness. Washington, DC: National Academies Press. <https://www.ncbi.nlm.nih.gov/pubmed/25695122>. (Note: In 2017, the Institute of Medicine was renamed National Academy of Medicine)

Twisk FNM. (2017), Dangerous exercise. The detrimental effects of exertion and orthostatic stress in myalgic encephalomyelitis and chronic fatigue syndrome. *Phys Med Rehabil Res*: <http://dx.doi.org/10.15761/PMRR.1000134>

⁴ Chowdhury et al., 2016

⁵ Geraghty K, Hann M, and Kurtev S (2017), Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys. *Journal of Health Psychology*: <https://doi.org/10.1177/1359105317726152>

⁶ National Collaborating Centre for Mental Health (2018), The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms. Full implementation guidance: https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/nccmh-iapt-ltc-full-implementation-guidance.pdf?sfvrsn=de824ea4_2

⁷ Science 4 ME, The PACE trial controversy: A Summary: <https://www.s4me.info/docs/PaceBriefing3.pdf>

⁸ Levin, B. (2018), How not to conduct a randomized clinical trial. Columbia University, Irving Medical Center: <http://www.virology.ws/2018/09/18/trial-by-error-bruce-levin-on-how-not-to-conduct-a-randomized-clinical-trial/>

⁹ Neary et al. (2008)
Peterson et al. (1994)

¹⁰ Miller et al. (2015)

¹¹ Snell et al. (2013)

Vermeulen, R. C., & Vermeulen van Eck, I. W. (2014), Decreased oxygen extraction during cardiopulmonary exercise test in patients with chronic fatigue syndrome. *Journal of Translational Medicine*, 12, 20. <http://doi.org/10.1186/1479-5876-12-20>

¹² Emerge Australia (2018), Report of key findings, 2018, Health and Wellbeing Survey of Australians with ME/CFS: <https://emerge.org.au/wp-content/uploads/2018/09/Emerge-Australia-Health-and-Wellbeing-Survey-of-Australians-with-MECFS-2018.pdf>

¹³ ME Association (2015), Our Illness Management Report on CBT, GET and Pacing calls for major changes to therapies offered for ME/CFS. 29 May 2015 <https://www.meassociation.org.uk/2015/05/23959/>

¹⁴ * Actimeters: no improvement in physical activity -- How does cognitive behavioral therapy reduce fatigue in patients with chronic fatigue syndrome? <https://www.ncbi.nlm.nih.gov/pubmed/20047707>

* No improvement in VO₂ max, fewer able to work, more on illness benefits: Stordeur S, Thiry N and Eysen M (2008) Chronisch Vermoeidheidssyndroom: Diagnose, behandeling en zorgorganisatie IFatigue Syndrome: Diagnosis, treatment and organisation of care. Technical report 88A (in Dutch). https://kce.fgov.be/sites/default/files/page_documents/d20081027358.pdf

* More people on illness benefits, no differences between groups (GET, CBT, pacing, control groups) McCrone P, Sharpe M, Chalder T, Knapp M, Johnson AL, et al. (2012) Adaptive pacing, cognitive behaviour therapy, graded exercise, and specialist medical care for chronic fatigue syndrome: a cost-effectiveness analysis. *PLoS One* 7: e40808.

ENDNOTES

- ¹⁵ ME Association (2015), Our Illness Management Report on CBT, GET and Pacing calls for major changes to therapies offered for ME/CFS. 29 May 2015 <https://www.meassociation.org.uk/2015/05/23959/>
- ¹⁶ #MEAction (2018), UK: More than 250 GPs attended the ME workshop at the RCGP Conference: <https://www.meaction.net/2018/10/18/over-250-gps-attend-me-workshop-rcgp-conference/>
- ¹⁷ Tymes Trust, Quick Tour of ME Symptoms, Management and Trust Service: <https://www.tymestrust.org/pdfs/quicktour.pdf>
- ¹⁸ Dowsett EG and Colby J (1997), Long Term Sickness Absence due to ME/CFS in UK Schools: An Epidemiological Study with Medical and Educational Implications
- ¹⁹ Action for ME (2017), Families facing false accusations: results of Action for M.E.'s survey: <https://www.actionforme.org.uk/uploads/pdfs/families-facing-false-accusations-survey-results.pdf>
- ²⁰ * Actimeters: no improvement in physical activity -- How does cognitive behavioral therapy reduce fatigue in patients with chronic fatigue syndrome? <https://www.ncbi.nlm.nih.gov/pubmed/20047707>
* No improvement in VO₂ max, fewer able to work, more on illness benefits: Stordeur S, Thiry N and Eyssen M (2008) Chronisch Vermoeidheidssyndroom: Diagnose, behandelning en zorgorganisatie [Fatigue Syndrome: Diagnosis, treatment and organisation of care]. Technical report 88A (in Dutch). https://kce.fgov.be/sites/default/files/page_documents/d20081027358.pdf
* More people on illness benefits, no differences between groups (GET, CBT, pacing, control groups) McCrone P, Sharpe M, Chalder T, Knapp M, Johnson AL, et al. (2012) Adaptive pacing, cognitive behaviour therapy, graded exercise, and specialist medical care for chronic fatigue syndrome: a cost-effectiveness analysis. PLoS One 7: e40808.