



## DEBATE PACK

Number CDP 2019/0014, 22 January 2019

# Appropriate ME treatment

This pack has been prepared ahead of the debate to be held in the Commons Chamber on Thursday 24 January 2019 on appropriate ME treatment. The subject for this debate has been determined by the Backbench Business Committee. The motion to be debated is

That this House calls on the Government to provide increased funding for biomedical research for the diagnosis and treatment of ME, supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment, supports updated training of GPs and medical professionals to ensure that they are equipped with clear guidance on the diagnosis of ME and appropriate management advice to reflect international consensus on best practice, and is concerned about the current trends of subjecting ME families to unjustified child protection procedures.

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

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# 1. Appropriate ME treatment

A debate on appropriate ME treatment will be held in the Commons chamber on 24 January 2019. The subject of the debate was decided by the Backbench Business Committee, and the debate will be led by Carol Monaghan MP, Nicky Morgan MP and Ben Lake MP.

The motion of the debate is:

That this House calls on the Government to provide increased funding for biomedical research for the diagnosis and treatment of ME, supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment, supports updated training of GPs and medical professionals to ensure that they are equipped with clear guidance on the diagnosis of ME and appropriate management advice to reflect international consensus on best practice, and is concerned about the current trends of subjecting ME families to unjustified child protection procedures.

## 1.1 Background

Myalgic Encephalomyelitis (ME), also referred to as Chronic Fatigue Syndrome (CFS/ME) is a long-term neurological condition. Estimates on number of people affected in the UK vary between 190,000<sup>1</sup> to 260,000.<sup>2</sup>

The most common symptom is persistent fatigue that is not relieved by rest or sleep. A briefing prepared by a number of CFS/ME organisations prior to a June 2018 Westminster Hall debate (and reproduced for the debate on 24 January 2019) describes the fatigue that is associated with CFS/ME and other symptoms individuals may experience:

People with ME experience severe, persistent fatigue associated with post-exertional malaise (PEM), their systems' inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms. PEM means that simple mental or physical activities can leave people with ME debilitated, experiencing a range of symptoms that are not significantly relieved by resting. PEM is the hallmark symptom of ME, other symptoms can include muscle and joint pain, cognitive difficulties, noise and light sensitivities and digestive problems.<sup>3</sup>

The presentation of CFS/ME can be variable (both between individuals and day to day for the same individual) with mild through to very severe symptoms. The effects of CFS/ME can affect an individual's life in a number of ways. Severe fatigue can make it very difficult to undertake many normal everyday activities and some people will have to adapt their lifestyles. Some people cannot maintain employment, and children may not be able to attend school which can result in their education being affected. CFS/ME can also affect people's emotional and mental health.

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<sup>1</sup> NICE, [NICE to begin review of its guidance on the diagnosis and treatment of CFS/ME](#), September 2017

<sup>2</sup> 2020health and Optimum Health Clinic Foundation, [Counting the cost: chronic fatigue syndrome/myalgic encephalomyelitis](#), September 2017

<sup>3</sup> ME Association, [Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis](#), January 2019

Individuals with severe ME can be significantly affected, may be housebound, spend extended periods in bed and require support from carers.

A 2017 report from the thinktank 2020health and the Optimum Health Clinic Foundation reported that the cost of CFS/ME to the UK economy was at least £3.3 billion in 2014/15.<sup>4</sup>

More information about the symptoms and effects of CFS/ME is provided in the following sources:

- NHS Choices, [Chronic fatigue syndrome \(CFS/ME\)](#), May 2017
- ME Association, [What is ME? Symptoms, testing, and assessment](#), 2018
- Action on ME, [Newly diagnosed with M.E./CFS](#), 2016 and [Living with M.E.](#)

## 2. Treatment for CFS/ME

The motion for the debate on 24 January 2019 is focused on the treatment of CFS/ME. It calls for increased funding for research in this area, and for the suspension of Graded Exercise Therapy and Cognitive Behavioural Therapy as treatment. It also calls for the training of healthcare professionals in the diagnosis and management of CFS/ME.

This section will provide an overview of the treatments that may be offered for individuals with CFS/ME, criticisms of clinical guidelines and some research undertaken in this area, and the ongoing update of these guidelines.

### 2.1 Current Treatments

The [cause of CFS/ME](#) is unknown, but a number of causes have been suggested. These include that a viral infection could trigger the condition or that it may be related to problems with the immune system, a hormonal imbalance or genetic factors.<sup>5</sup> There is no cure for this condition, treatment is primarily focused on addressing the symptoms.

The NHS Choices website states that there is “*no single way of managing CFS/ME that works for everyone, but there are a number of treatment options.*”<sup>6</sup>

Treatment options that may be offered in treating CFS/ME, include:

- Cognitive Behavioural Therapy (CBT) - a talking therapy that aims to help individuals manage CFS/ME;
- Graded Exercise Therapy (GET) - a structured exercise programme that aims to increase an individual’s physical activity;

<sup>4</sup> 2020health and Optimum Health Clinic Foundation, [Counting the cost: chronic fatigue syndrome/myalgic encephalomyelitis](#), September 2017

<sup>5</sup> NHS Choices, [Chronic fatigue syndrome \(CFS/ME\)](#), 2017

<sup>6</sup> NHS Choices, [Chronic fatigue syndrome \(CFS/ME\)](#), 2017

- Activity management- a technique that involves setting individual goals and gradually increasing activity levels;
- Medications which may treat certain symptoms (such as pain relief medicines for muscle pain and headaches, and anti-depressants which may be used in patients who are having problems sleeping); and
- Lifestyle changes- these can include changes to diet and sleep practices.<sup>7</sup>

## 2.2 Review and criticism of current treatments

### Clinical guidelines

The National Institute for Health and Care Excellence (NICE) produces evidence-based information for the NHS on the effectiveness and cost-effectiveness of healthcare interventions. It publishes mandatory technology appraisal guidance stipulating clinical interventions (mainly medicines) which must be funded by NHS commissioners, as well as advisory clinical guidelines and public health guidance.

In 2007, NICE produced the clinical guideline, [Chronic Fatigue Syndrome/Myalgic Encephalomyelitis \(or encephalopathy\): Diagnosis and management](#). The guideline sets out best practice on the diagnosis, treatment, care and support of children and adults with CFS/ME and advises local NHS commissioners and clinicians on the delivery of services.

In 2017, NICE conducted a review of this guideline. It initially decided that it did not think that the new evidence available would lead to a change in the guideline. However, a strong response to the consultation on this decision highlighted broader issues in relation to the guideline, and NICE announced in September 2017 that it would fully update them.<sup>8</sup> The Chief Executive of NICE, Sir Andrew Dillon said that the “strong message from stakeholders was that the continuing debate about the causes of this condition and the best approach to treatment argued for a review of the current guideline.”<sup>9</sup>

Concerns raised both in the consultation, and prior to this, included that:

- Changes to diagnostic criteria should be considered (new criteria are being used, see for example, the US Institute of Medicine (2015)<sup>10</sup> and the International Consensus Criteria (2011)<sup>11</sup>);

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<sup>7</sup> NHS Choices, [Chronic fatigue syndrome \(CFS/ME\): Treatment](#), 2017

<sup>8</sup> NICE, [Surveillance report 2017 – Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management \(2007\) NICE guideline CG53](#), September 2017

<sup>9</sup> NICE, [NICE to begin review of its guidance on the diagnosis and treatment of CFS/ME](#), September 2017

<sup>10</sup> Institute of Medicine, [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#), 2015

<sup>11</sup> B M Carruthers et al, [Myalgic encephalomyelitis: International Consensus Criteria \(Review\)](#). *J Intern Med* 2011; **270**: 327–338.

- severe ME is not well covered in the guideline;
- there has been variability in the adoption of the NICE guidance; and
- new evidence on treatment approaches should be considered.<sup>12</sup>

In February 2018, NICE reported on the next steps of the guideline update, including that a scoping workshop had been held with stakeholders.<sup>13</sup> The final scope of the guideline was published in October 2018.<sup>14</sup>

The updated NICE guideline is due to be published in October 2020.<sup>15</sup>

In response to a Westminster Hall debate in June 2018, the Under-Secretary of State for Health and Social Care, Steve Brine, highlighted patient concerns about the current NICE guideline and welcomed the update to these:

A lot was said about NICE guidelines, which are clearly a sensitive topic and a source of much unhappiness among Members and the wider ME community. According to NICE guidelines, recommended treatments for ME include cognitive behavioural therapy and graded exercise therapy. I know that many patients disagree with those treatments, and we heard powerful testimony about that. The NICE guideline is clear that there is no one form of treatment to suit every patient; that the personal needs and preferences of the patient should be taken into account; that doctors should explain that no single strategy will be successful for all patients; and that, in common with all people receiving NHS care, ME patients have the right to refuse or withdraw from any part of their treatment that they do not agree with or they think is doing them harm.

As we heard, the NICE guideline is being updated—a jolly good job, too. NICE will look at the current evidence base, including the PACE trial, which has been debated at length in the House before. Of course, we welcome NICE's decision to undertake a full review of ME guidelines. Many of the ME charities we have heard about today are registered to take part in the guideline development process, but NICE is the independent expert body responsible for developing robust, evidence-based guidance for the NHS to design services that are in line with the best available evidence, and no one should hide from the evidence. It would be inappropriate and wrong for Ministers to interfere with the process, but I feel sure that NICE will be listening to the debate and taking a keen interest in it.<sup>16</sup>

<sup>12</sup> NICE, [Surveillance report 2017 – Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management \(2007\) NICE guideline CG53](#), September 2017

<sup>13</sup> NICE, [NICE announces next steps in updating its guideline on ME/CFS](#), February 2018

<sup>14</sup> NICE, [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management, project documents](#) (accessed 22 January 2019)

<sup>15</sup> NICE, [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#) (accessed 22 January 2019)

<sup>16</sup> [HC Deb 21 June 2018 C231WH](#)

On 11 January 2019, the ME association reported that NICE had asked a number of charities to gather further information on patients' experiences of GET and CBT.<sup>17</sup>

## The PACE Trial

Concerns have been raised about the use of evidence in the NICE guideline from clinical trials, such as the PACE trial.<sup>18</sup>

The PACE trial was a large-scale trial looking at four different treatments available for CFS/ME. It was conducted by teams at Queen Mary, University of London and Kings College London. The 600 participants in the trial were randomly assigned to one of four treatments for a period of 12 months.<sup>19</sup>

In the submission to the Backbench Business committee, Carol Monaghan highlighted concerns about the PACE trial, the recommendation of treatments that patients have reported to be harmful, and the ongoing update of the NICE guidance:

However, I met a constituent in January this year who told me about something called the PACE trial. It is a piece of fairly controversial research that recommended that the best treatment for people with ME is something called graded exercise therapy. From the start, the ME community has argued that this treatment is not only ineffective but is extremely damaging, with people who have undertaken it ending up far worse than they started.

[...]

The timing is important. The National Institute for Health and Care Excellence is currently updating its guidelines for the treatment of ME, as a result of the pressure that the ME community put on it because of its current recommendation for graded exercise therapy. There is concern that graded exercise therapy will remain because over 60% of the panel—it is called the guideline development group—are supporters of PACE. It calls into question the independence of this particular review of current treatments.

### What were the findings of the PACE trial?

The findings of the PACE trial were [published in the Lancet in 2011](#). In summary, the trial concluded that cognitive behavioural therapy (CBT) and graded exercise therapy (GET) when combined with standardised specialist medical care were more effective in reducing fatigue and improving functioning than standardised specialist care alone, or standardised specialist care with adaptive pacing therapy. The PACE trial supported the findings of previous smaller trials looking at the same subject. More information is provided on [the trial website](#).

[A 2016 Cochrane review](#)<sup>20</sup> has since looked at the use of exercise in the management of patients with CFS. The review looked at randomised controlled trials published up to May 2014, it included eight studies

<sup>17</sup> ME Association, [NICE ME/CFS Guideline Review: CBT and GET Patient Survey](#), 11 January 2019

<sup>18</sup> [Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome \(PACE\): a randomised trial](#) White, PD et al. The Lancet, Volume 377, Issue 9768, 823 - 836

<sup>19</sup> [The Wolfson Institute, Pace Trial: Overview](#)

<sup>20</sup> A Cochrane Review is a systematic review of research in health care and health policy. More information is available on the [Cochrane Library website](#).

(including the PACE trial) with a total of 1,518 participants. The review concluded that moderate quality evidence showed that exercise therapy was more effective at reducing fatigue compared to passive treatment (e.g. waiting list, treatment as usual, relaxation, flexibility) or no treatment and that it had a positive effect on people's daily physical functioning. The researchers suggested that further studies should be used to look at what type of exercise is the most beneficial for people with CFS. More detailed information about the review is provided on [the Cochrane website](#).

### Criticisms of the PACE trial and reanalysis of trial data

There have been a number of criticisms of the methods used in the PACE trial and concerns that these led to an inflation in the reported efficacy of certain interventions.<sup>21</sup>

Several applications under the Freedom of Information Act for the release of the data from the trial were refused by the trial authors who argued that publication may mean that patients could be identified.<sup>22</sup> In October 2015, the Information Commissioner decided that the data should be released<sup>23</sup> and at appeal, a tribunal agreed with this decision.<sup>24</sup>

Following the release of the PACE trial data, published reanalyses have reported that the benefits of the treatments in the trial were modest and were not long term.<sup>25,26</sup> However, the PACE trial authors have defended the results of the trial<sup>27</sup> and have responded to criticisms in medical journals<sup>28</sup> and on the PACE trial webpage.<sup>29</sup>

In August 2018, an open letter was sent to the Lancet calling on the journal to commission an independent reanalysis of the data from the PACE trial. This was signed by over a hundred academics, patient groups, healthcare professionals and MPs.<sup>30,31</sup> It highlighted the

<sup>21</sup> For example, Geraghty, K. J. (2017). Further commentary on the PACE trial: Biased methods and unreliable outcomes. *Journal of Health Psychology, 22*(9), 1209–1216. <https://doi.org/10.1177/1359105317714486> and Shepherd, C. B. (2017). PACE trial claims for recovery in myalgic encephalomyelitis/chronic fatigue syndrome – true or false? It's time for an independent review of the methodology and results. *Journal of Health Psychology, 22*(9), 1187–1191. <https://doi.org/10.1177/1359105317703786>

<sup>22</sup> The PACE trial authors had allowed some access to the data, including to Cochrane researchers.

<sup>23</sup> [Freedom of Information decision notice](#), 27 October 2015

<sup>24</sup> Ingrid Torjesen, [Tribunal orders university to release data from PACE chronic fatigue study](#), BMJ, 22 August 2016

<sup>25</sup> Wilshire et al, [Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT](#), BMC Psychology, 2018, Volume 6, Number 1, Page 1

<sup>26</sup> Wise Jacqui, [Reanalysis of PACE trial reignites row over chronic fatigue treatment](#) BMJ 2016; 354 :i5230

<sup>27</sup> Science Media Centre, [expert reaction to reanalysis of the PACE trial for chronic fatigue syndrome \(CFS\) treatments](#), 22 March 2018

<sup>28</sup> Examples include [Response to the editorial by Dr Geraghty](#) Peter D White et al, *Journal of Health Psychology* Vol 22, Issue 9, pp. 1113 – 1117, January 2017 and White, P., Chalder, T., & Sharpe, M. (2015). [The planning, implementation and publication of a complex intervention trial for chronic fatigue syndrome: The PACE trial](#). *BJPsych Bulletin, 39*(1), 24-27. doi:10.1192/pb.bp.113.045005

<sup>29</sup> The Wolfson Institute, [Pace trial: FAQs](#) (accessed 22 January 2019)

<sup>30</sup> Virology Blog, [Trial By Error: Open Letter to The Lancet, version 3.0](#), 13 August 2018

<sup>31</sup> Tom Whipple, [Call for review of 'flawed' ME research in Lancet letter](#), The Times, 21 August 2018



findings of the re-analyses of the PACE trial data, and that international health organisations, such as the US Centers for Disease Control had removed recommendations of GET and CBT for the treatment of CFS/ME and had also called for a reanalysis of the trial results.

The Executive Chair of the Medical Research Council (MRC) (who funded the PACE trial), Professor Fiona Watt, responded in a [letter to the Times](#). She said that the MRC rejected the view that the scientific evidence from the PACE trial was unsound:

[...] as funders of the Pace trial we reject the view that the scientific evidence provided by the trial for using cognitive behavioural theory and managed exercise in the treatment of chronic fatigue syndrome (also known as ME) was unsound. The Pace trial was funded following expert peer review, was overseen by an independent steering committee, and its published findings have also been independently peer-reviewed. Other research groups have drawn similar conclusions.<sup>32</sup>

An extended version of this letter is published on [the MRC website](#).<sup>33</sup>

## 2.3 Training and awareness

Another issue raised by stakeholders is a need for greater awareness amongst healthcare professionals of CFS/ME. This issue was addressed by Steve Brine in response to a June 2018 debate on ME Treatment and research:

The Royal College of General Practitioners oversees GP training in England. It provides an online course for GPs and other primary care practitioners that includes an overview of the presentation, diagnosis, assessment and ongoing management of ME. The course highlights common misconceptions about ME and considers the challenges that surround that complex condition for patients, carers and primary care professionals. It is produced as part of the METRIC study, which is funded by the NIHR.

Of course GPs can always know more and learn more, but let me speak up for them for a moment. They are called “general practitioners”. Be a GP for a day—it is incredibly difficult to know everything about everything and to be a master of all. General practice is, though, where most patients with ME are likely to be managed, certainly in the first instance. The condition is identified as a key area of clinical knowledge in the RCGP applied knowledge test content guide. The AKT is a summative assessment of the knowledge base that underpins general practice in England and a key part of GPs’ qualifying exams.

Although I understand hon. Members’ points about raising awareness among medical professionals, and as a result of the debate I will redouble my efforts to do that as part of my role as Minister for primary care, all GPs certainly should be aware of ME, and should maintain their clinical knowledge of it and other conditions, as part of their commitment to continuing professional development. Indeed, I have resolved—I have already sent a note to myself—to send a copy of the report of the debate to Professor

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<sup>32</sup> The Times, [Letters: Chronic fatigue](#), 27 August 2018

<sup>33</sup> MRC, [Criticism of the PACE trial](#), 28 August 2018



Helen Stokes-Lampard, who currently leads the RCGP, and to ask for the college's latest thinking about this subject.<sup>34</sup>

### 3. Research on CFS/ME

Patients and CFS/ME organisations are calling for increased funding for biomedical research to improve knowledge of the potential causes and effects of CFS/ME. They report that this condition has received far less funding for research than other conditions with similar prevalence and disease burden and that this funding has tended to be for psychological and behavioural studies rather than biomedical research.<sup>35</sup>

Carol Monaghan MP explained the call for more biomedical research funding for CFS/ME in a June 2018 article on the Politics Home website:

To develop effective treatments, we need a more realistic approach to biomedical research. A recent study by researchers at Columbia University found that there were specific patterns in immune biomarkers in people with ME, and some patients have reported improvements in their condition as a result of courses of antiviral drugs. But how can we genuinely consider that we are able to provide treatments for a condition that we as yet do not understand?

Since the start of the year, I have been pressing the government for significantly increased funding for biomedical investigation. Recent parliamentary questions reveal that the average research spend per person living with ME is around £1 per year, much of which is funded, not by government, but by ME charities. Compared to the economic cost of lost days at work, unemployment, and disability benefits, this is simply unacceptable. However, because of the nature of the condition, those with ME are often unable to campaign. One group's name, "Millions Missing", is an accurate description of the uphill battle faced while attempting to bring about change from a sick bed.<sup>36</sup>

#### Government funding for CFS/ME research

The Government currently funds health related research through two main routes, the National Institute for Health Research (NIHR) and the UK Research Councils (mainly through the Medical Research Council – MRC). Broadly, the NIHR is responsible for allocating research funding to NHS organisations (typically NHS Trusts), whilst the MRC provides research grants and career awards to scientists in UK universities and hospitals.

Figures on research expenditure for specific conditions are not easily obtainable. Research Council annual accounts detail funding allocations by the institution that receives them rather than the research purpose. Meanwhile, individual NHS organisations' programme budgets do not break down their expenditure in the way required to identify CFS/ME research funding.

<sup>34</sup> [HC Deb 21 June 2018 C231WH](#)

<sup>35</sup> ME Association, Action for M.E., ME Trust and #ME action, [Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis Treatment and research](#), 12 June 2018

<sup>36</sup> Carol Monaghan, [We must change perception of the debilitating disease ME, Politics Home](#), 18 June 2018

However, some information on funding for Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME) is available from PQ responses. The table below gives details of NIHR funding for biomedical research into CFS/ME from 2013/14 to 2017/18.

<b>NIHR FUNDING FOR CFS/ME RESEARCH</b>	
2013-14	£561,950
2014-15	£426,055
2015-16	£475,676
2016-17	£554,785
2017-18	£464,902

[Source: PQ 181584, 29 October 2018](#)

Some information is also available on funding for biomedical research into CFS/ME by the NIHR Clinical Research Network (CRN) (separate from the funding set out above). This organisation provides the infrastructure to allow clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the National Health Service. The level of funding for biomedical research into CFS/ME from 2014-15 to 2016-17 is shown in the table below. Expenditure from the CRN Coordinating centre is also shown. Details of overall CFS/ME research funding are not available.

<b>NIHR CRN FUNDING FOR BIOMEDICAL CFS/ME RESEARCH</b>		
	CRN funding	Coordinating expenditure
2014-15	£134,769	£17,485
2015-16	£125,176	£17,796
2016-17	£82,866	£7,821

[Source: PQ 145356, 22 May 2018](#)

Finally, details of MRC expenditure research into CFS/ME are shown below.

<b>MRC SPENDING CFS/ME RESEARCH</b>	
2014-15	£652,044
2015-16	£287,234
2016-17	£286,197

[Source: PQ 145356, 22 May 2018](#)

The Government have set out recently what action is being taken to encourage more research in this area:

The Department National Institute for Health Research (NIHR) recognises that chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a debilitating condition. The NIHR is speaking with the United Kingdom's CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

The NIHR welcomes funding applications for research into any aspect of human health, including CFS/ME; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.<sup>37</sup>

## 4. News items

Guardian

**Chronic fatigue syndrome 'could be triggered by overactive immune system'**

17 December 2018

<https://www.theguardian.com/society/2018/dec/17/chronic-fatigue-syndrome-could-be-triggered-by-overactive-immune-system>

BMJ

**Pressure grows on *Lancet* to review "flawed" PACE trial**

22 August 2018

BMJ 2018;362:k3621

<https://www.bmj.com/content/362/bmj.k3621>

BBC News Online

**Chronic fatigue syndrome treatment 'should be withdrawn'**

8 May 2018

<https://www.bbc.co.uk/news/newsbeat-44004882>

Independent

**Time for Unrest: Why patients with ME are demanding justice**

7 January 2018

[https://www.independent.co.uk/news/long\\_reads/why-patients-me-demanding-justice-millions-missing-chronic-fatigue-illness-disease-a8133616.html](https://www.independent.co.uk/news/long_reads/why-patients-me-demanding-justice-millions-missing-chronic-fatigue-illness-disease-a8133616.html)

BBC News Online

**Carers of children with ME 'accused of fabrication'**

27 June 2017

<https://www.bbc.co.uk/news/uk-england-40407174>

## 5. Press releases

### Action for M.E.

#### Scottish government launches National Action Plan

January 16, 2019

The Scottish Government has published a draft [National Action Plan on Neurological Conditions](#). It sets out the vision of improving diagnosis, treatment and care of people with neurological conditions in Scotland.

The aims of the plan are to:

- Ensure people with neurological conditions and their carers are partners in their care and support
- Improve the provision of coordinated health and social care and support for people with neurological conditions
- Ensure high standards of effective, person-centred, and safe care and support
- Improve equitable and timely access to health and social care and support across Scotland
- Build a sustainable neurological workforce for the future.

This plan was developed in response to a lived experience survey of people living with neurological conditions. 33% of the 588 responses to the survey were from people living with M.E. in Scotland. However, Action for M.E. are disappointed that the published report on the survey included very little analysis of the data acquired from people with M.E. instead focusing on Alzheimer's disease, tension type headache, epilepsy, multiple sclerosis, Parkinson's disease and Motor neurone disease. If M.E. were to have been included it would have been Scotland's fourth most prevalent disease.

Action for M.E. are taking the time to respond to this plan and highlight areas where this plan will affect the lives of people with M.E./CFS. In particular, we would like to see the introduction of specialist services for people with M.E./CFS and trained healthcare professionals who can take a lead in its delivery.

We will publish our response shortly but in the meantime, we would encourage people to read the document and [access the consultation](#) if they have any comments or concerns they would like to add.

### ME Association

#### NICE ME/CFS Guideline Review: CBT and GET Patient Survey

11 January 2019

The Forward ME group of charities has been asked by NICE to gather further evidence and experiences of Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) from people who have a clinical diagnosis of ME/CFS/PVFS and who were resident in the UK.

Commenting on the survey, the Chair of Forward ME group, the Countess of Mar, said:

We are sure that you will recognise how important it is that the new NICE guideline reflects the real situation of people with ME and that, by completing this survey you will be helping the committee to reach informed conclusions that will be the basis of their recommendations for the new guideline.

The survey will be independently analysed by a team from Oxford Brookes University, before being submitted to NICE at the end of February.

The deadline for completing the questionnaire is the 31st January 2019, to meet the very narrow timeframe set out by NICE.

Unfortunately, this also means that Forward ME do not have the time or capacity to send out/accept paper copies. We will make it very clear to NICE when we submit the report that those unable to complete the survey online, including many severely affected people, have not been able to take part.

The survey is however designed to allow a carer, parent or another person to fill it in on behalf of someone else if they are unable to do this themselves.

The survey is designed for adults and children who have been diagnosed with ME, CFS or PVFS and who have undertaken or were offered CBT or GET in the UK since 2007. All responses collected in this survey will be anonymous.

You can find the survey, [HERE](#) or click the image above.

## **ME Association**

### **NICE ME/CFS Guideline Review: Publication of revised Scope, comments, and committee appointments**

**16 October 2018**

The scope report provides the framework for the review that the NICE guideline committee will follow during their deliberations. The initial draft scope has been revised and published and should now be regarded as final.

This followed [stakeholder feedback on the draft report](#) back in August.

You can read all the comments the draft report attracted, together with the responses from NICE, below:

- [Final Scope](#)
- [Consultation comments and responses](#)

As there is quite a lot of information to read, we felt it was best to publish it now before and if we make any comment ourselves.

*The ME/CFS guideline consultation committee*

It would seem from the documents now available on the [NICE website](#), that certain members of the guideline committee have now been appointed. These include the chair and vice-chair and several core members like Dr Luis Nacal from the ME/CFS Biobank in his capacity as GP, as well as the important lay members.

- [Committee member list](#)

We would like to take this opportunity to congratulate all members and wish them well in the task ahead. It is our hope that the revised ME/CFS clinical guideline will be a significant improvement over the current one.

Once the committee are all appointed, the process will continue with a new draft guideline expected in 2020. At that point, stakeholders will again have the opportunity to comment and influence the final clinical guideline. Until then, it's a rather anxious period of waiting to see what they might come up with.

The NICE guideline is important as it does influence how patients are treated by the NHS. It affects those who present with suspected symptoms, the method of diagnosis and of testing, and the advice that patients and carers receive with regard to the all important management options.

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NICE | The National Institute for Health and Care Excellence

Guidance, advice and information services for health, public health and social care professionals.

Dear Colleague,

RE: NICE guideline on Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management (Oct 2020)

The final scope and equality impact assessment for this NICE guideline have now been [published](#), along with all the [stakeholder comments](#) that were received during consultation and our responses to these comments.

We would like to thank you for your continued involvement and interest in this guideline. The comments received during the consultation period helped us to develop and refine the scope.

Your organisation has been identified as a key stakeholder for this topic; we will contact you again when the draft guideline is released for consultation and ask that you please prioritise sending us your comments.



If you have any further queries, please contact  
[CFSME@nice.org.uk](mailto:CFSME@nice.org.uk).

Kind regards,

The National Institute for Health and Care Excellence

## **Medical Research Council**

### **Criticism of the PACE trial**

**28 Aug 2018**

The Times recently reported on a letter to [The Lancet](#) which called for the journal to reanalyse the data from the PACE trial. Independent scrutiny and analysis are to be welcomed in the quest for robust and reproducible research results. The MRC is keen to encourage more research into different aspects of CFS/ME because scientists still know relatively little about this serious condition.

Executive Chair, Professor Fiona Watt, responded in a [letter to the Times](#) (27 August 2018), an extended version of which appears here:

[‘Call for review of ‘flawed’ ME research’](#) (The Times, 21 August 2018) discusses claims that the scientific evidence provided by the PACE trial for using cognitive behavioural therapy (CBT) and managed exercise in the treatment of chronic fatigue syndrome (CFS, also known as ME) is fundamentally unsound.

As funders of the trial, we reject that view: the PACE trial was funded following expert peer review, was overseen by an independent steering committee, and its published findings were also independently peer reviewed. The process through which PACE was funded, supervised and published therefore meets international standards for clinical trials.

CFS/ME is considered to be a spectrum of disorders and understanding the causes and informing the development of new treatments, or the targeting of existing treatments, will require research across a range of approaches and from a holistic view point. The PACE trial investigated the important issue of which available treatments were most likely to benefit patients, and patient consultation resulted in the addition of a treatment to the trial.

While most of the criticism focuses on the PACE trial, there is a large amount of evidence from other studies that also shows CBT and graded exercise therapy (GET) can be helpful to some CFS/ME patients. Other research groups, using different study designs, have drawn similar conclusions about the benefit of these treatments. This evidence is summarised in three Cochrane reviews. Cochrane reviews are systematic reviews of primary research in human healthcare and health policy, and are internationally recognised as the gold standard in evidence-based healthcare.

*Making the data available*

One criticism of the PACE trial has been that the data is not widely available to other researchers for use in further research and to confirm the reproducibility of results. The MRC strongly supports the sharing of data from clinical trials but it is critical that sensitive personal information from study participants is not released when study data is shared. We are currently supporting the PACE trial investigators to anonymise the study data from over 600 participants so that it can be made available to other researchers in a way that protects the privacy of those patients who took part.

The MRC has recently started (with other research funders) a pilot of a new facility for academic researchers to share data via the [Clinical Study Data Request](#) (CSDR) web portal. We hope to include the PACE trial on the CSDR portal within the next 6-12 months. This will allow researchers to apply to the CSDR Independent Review Panel to gain access to the dataset for their own analyses.

#### *Apply for CFS/ME research funding*

CFS/ME is a serious illness that is estimated to affect around 0.2-0.4% of the UK population and it remains a research priority for the MRC. The MRC has undertaken and is actively engaged in a number of strategic activities to promote and encourage research into the causes of this condition and effective treatments, and to support the research community. Activities have included a dedicated funding call – [Understanding the mechanisms of CFS/ME](#) – in 2011. We want to encourage a broad range of scientists, some of whom are wary of this controversial area, to apply to us for funding. At present, response-mode applications are encouraged through a cross-board [highlight notice](#) to undertake innovative research into the mechanisms underlying the chronic changes associated with CFS/ME, particularly in relation to immune regulation, pain, different symptom profiles, childhood CFS/ME and neurological inflammation.

The MRC also supports the UK CFS/ME Research Collaborative (CMRC): a platform for patients, researchers, clinicians and funders to coordinate strategies to increase awareness of the condition within the research community and increase research funding.

### **Action for M.E.**

#### **Action for M.E. to sign open letter to Lancet**

**June 20, 2018**

Yesterday, Prof Vincent Racaniello, Columbia University, sent [a letter to The Lancet](#) about the PACE trial, asking the journal to “commission an independent re-analysis of the individual-level trial data, with appropriate sensitivity analyses, from highly respected reviewers with extensive expertise in statistics and study design.”

Having contacted David Tuller, who helped circulate the letter and published it on his blog, Action for M.E.’s Chief Executive Sonya

Chowdhury has confirmed that she will sign it on behalf of the organisation. We understand that, over the next few days, the option to support the letter will also be offered to other charities and advocacy organisations.

Already co-signed by more than 90 international clinicians and researchers, the letter highlights that:

- the behavioural treatments CBT and GET tested in the PACE trial, the results of which were published in the Lancet in 2011, were “based on the hypothesis that ME/CFS patients harbor ‘unhelpful’ convictions about having an ongoing organic disease and that the perpetuation of their devastating symptoms is the result of deconditioning”
- by contrast, a 2015 report by the US Institute of Medicine (now the National Academy of Medicine) makes it clear that the defining symptom of the condition is “a systemic intolerance to exertion; if patients exceed their available energy resources, they can suffer serious and prolonged relapses”
- a growing number of international health authorities, including the US Centers for Disease Control and the Dutch Health Council have stopped recommending CBT and/or GET as suitable treatments for M.E.
- earlier this year, leading American clinicians who specialise in M.E. “[unanimously agreed](#) that the two PACE treatments are inappropriate and possibly harmful for patients.”

## **National Institute for Health and Care Excellence**

### **NICE announces next steps in updating its guideline on ME/CFS**

**15 February 2018**

A workshop last month with stakeholders marked the formal start of NICE’s collaborative work to update its 2010 guideline on the diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

The workshop was held so that stakeholders, including patient groups for people with ME/CFS and their carers, could help NICE identify at an early stage the issues they consider most important for the development of the new guideline.

Over 45 people attended the workshop, representing 37 different organisations supporting people with ME/CFS.

NICE has also confirmed the next steps in the development of the new guideline, starting with a further workshop with stakeholder organisations on 25 May to discuss the scope of the guideline. Stakeholders will then have the opportunity to comment on the draft scope between 21 June and 19 July. This will coincide with recruitment to the independent guideline committee, which will also begin on 21 June with adverts posted on the [NICE website](#).

Professor Mark Baker, director of the NICE centre for guidelines, said:

We wanted to get the views and insights of as many people as possible who are affected, either directly or indirectly, by ME/CFS to make sure we understand the issues that are important to them.

The clear message from the workshop was the need to ensure the new guideline properly addresses and resolves the continuing debate about the best approach to treating people with this condition. It also confirmed our intention to ensure robust representation of people with ME/CFS, or their carers, on the independent committee that will develop the guideline.

Therefore, following the scoping workshop we're holding in May, we will recruit a guideline committee which will include 4 people with the condition or their carers, rather than the usual 2. Additionally, we will include a lay member on the recruitment panel for the chair of the guideline committee.

Once recruited, the committee will review a wide range of evidence and develop recommendations, based on the agreed scope of the guideline.

ME/CFS is a relatively common condition affecting around 190,000 people in the UK. It comprises a range of symptoms that includes fatigue, headaches, sleep disturbances, difficulty concentrating and muscle pain.

It can cause prolonged illness and disability and although some people have relatively mild symptoms and can still manage daily activities with additional rest, others have a more serious form of the illness that severely affects their everyday lives and can leave them housebound. The pattern of a person's symptoms, and their severity, can vary from day to day, or even in the same day.

Further details about the development of the new NICE ME/CFS guideline, including the timeline and information about how to get involved, either by sharing your views and experiences of ME/CFS, or by becoming a member of the guideline committee, are available on the [NICE website](#) or by emailing [CFSME@nice.org.uk](mailto:CFSME@nice.org.uk)

Our [public involvement](#) team is also on hand to advise members of the public and patient groups who wish to be involved in this work.

## 6. Parliamentary material

### Debate

#### **ME: Treatment and Research**

**HC Deb 21 June 2018 | Vol 643 c189WH**

<https://hansard.parliament.uk/Commons/2018-06-21/debates/A49A6117-B23B-4E35-A83B-49FEF0D6074F/METreatmentAndResearch#contribution-EDC65069-BC4C-4DA1-A913-F4C32C9B815B>

### PQs

#### [Chronic Fatigue Syndrome](#)

##### **Asked by: Hopkins, Kelvin**

To ask the Secretary of State for Health and Social Care, what discussions his Department has had with NICE on acceptance of the classification of myalgic encephalomyelitis as a neurological disease as defined by the World Health Organisation; and if he will make a statement.

##### **Answering member: Steve Brine | Department: Department of Health and Social Care**

The Department has had no such discussions. The National Institute for Health and Care Excellence (NICE) is an independent body and develops its guidance based on a thorough assessment of the available evidence and in consultation with stakeholders. NICE is currently updating its clinical guideline on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis, with expected publication on 14 October 2020.

**HC Deb 03 December 2018 | PQ196648**

#### [Chronic Fatigue Syndrome](#)

##### **Asked by: Ashworth, Jonathan**

To ask the Secretary of State for Health and Social Care, what assessment his Department has made of the prevalence of myalgic encephalopathy/chronic fatigue syndrome in England.

To ask the Secretary of State for Health and Social Care, what pharmacological treatments are available to people living with myalgic encephalomyelitis/chronic fatigue syndrome.

To ask the Secretary of State for Health and Social Care, what support his Department provides to people in the UK who have myalgic encephalomyelitis/chronic fatigue syndrome.

**Answering member: Steve Brine | Department: Department of Health and Social Care**

The National Institute for Health and Care Excellence (NICE) recommends treatments which have the clearest clinical evidence of benefit. There is no known pharmacological treatment or cure for myalgic encephalopathy/chronic fatigue (CFS/ME); however, the guidance is clear that there is no one form of treatment to suit every patient. People with CFS/ME should have the opportunity to make informed decisions about their care and treatment should be provided in line with their preferences.

The NICE guidance also provides clinical guidance on best practice which is used to support the local National Health Service shape services to support people with CFS/MS. The commissioning of services for people with CFS/ME is a local matter.

Overall evidence suggests that CFS/ME has a population prevalence of at least 0.2-0.4%. This would mean that a general practice with 10,000 patients is likely to include up to 40 people with CFS/ME. Estimates are based on extrapolations from other countries.

Further information on CFS/ME can be found via the following websites:

[www.nice.org.uk/guidance/cg53](http://www.nice.org.uk/guidance/cg53)

[www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/](http://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/)

[www.meassociation.org.uk/about/what-is-mecfs/](http://www.meassociation.org.uk/about/what-is-mecfs/)

**HC Deb 29 October 2018 | PQ 181653; PQ 181651; PQ 181652**

[Chronic Fatigue Syndrome](#)

**Asked by: Ashworth, Jonathan**

To ask the Secretary of State for Health and Social Care, how much his Department has spent on research into myalgic encephalomyelitis/chronic fatigue syndrome over the past five financial years.

**Answering member: Caroline Dinenage | Department: Department of Health and Social Care**

The following table shows information provided by the National Institute for Health Research (NIHR) on Departmental programme research funding for myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), over each of the last five years. Further information on this research is available through the NIHR Journals Library at the following link:

<https://www.journalslibrary.nihr.ac.uk/programmes/>

Financial Year £

2013-14	561,950
2014-15	426,055
2015-16	475,676
2016-17	554,785
2017-18	464,902

The NIHR recognises that CFS/ME is a debilitating condition and is speaking with the United Kingdom CFS/ME Research Collaborative and patient representatives about how best to support a joined up approach to high quality research into this complex disorder. The NIHR welcomes funding applications for research into any aspect of human health, including CFS/ME; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

**HC Deb 29 October 2018 | PQ 181584**

#### [Chronic Fatigue Syndrome](#)

**Asked by: Robertson, Mr Laurence**

To ask the Secretary of State for Health and Social Care, what recent assessment he has made of the adequacy of funding for research into the causes of ME; and if he will make a statement.

**Answering member: Caroline Dinenage | Department:  
Department of Health and Social Care**

The Department's National Institute for Health Research (NIHR) recognises that myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is a debilitating condition.

Since 2011, the NIHR has provided £3.37 million of programmes funding for projects and training on CFS/ME. Several of the NIHR's Biomedical Research Centres also carry out research into CFS/ME, with project funding provided by the Medical Research Council and CFS/ME charities.

The NIHR welcomes funding applications for research into any aspect of human health, including ME; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

**HC Deb 09 October 2018 | PQ 173506**

#### [Chronic Fatigue Syndrome: Medical Treatments](#)

**Asked by: Walker, Thelma**



To ask the Secretary of State for Health and Social Care, whether his Department plans to review NICE guidelines on the treatment of myalgic encephalomyelitis; and if he will make a statement.

**Answering member: Steve Brine | Department: Department of Health and Social Care**

The National Institute for Health and Care Excellence (NICE) is an independent body and is responsible for determining whether its guidance should be updated to take into account new evidence. NICE is currently updating its clinical guideline on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis and is consulting stakeholders on a draft scope for the guideline update.

**HC Deb 04 July 2018 | PQ 157851**

### [Chronic Fatigue Syndrome](#)

**Asked by: The Countess of Mar**

To ask Her Majesty's Government, further to the Written Answer by Lord O'Shaughnessy on 5 June (HL8135), what assessment they have made of the ethicality of the continued recommendation of graded exercise therapy and cognitive behavioural therapy to patients with myalgic encephalomyelitis or chronic fatigue syndrome, following scientific research demonstrating that such therapies are not effective and may harm patients with that illness, and the imminent update of NICE guideline CG53, published in 2007.

**Answering member: Lord O'Shaughnessy | Department: Department of Health and Social Care**

We are aware that there are concerns that more recent data and analysis suggests graded exercise therapy (GET) and cognitive behavioural therapy (CBT), which are recommended by the National Institute for Health and Care Excellence (NICE), for patients with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) might not be as effective as has been found by previous trial results. It is important that all the evidence, including new evidence, is looked at closely. We welcome NICE's decision to update its clinical guideline on CFS/ME and to examine the new analysis of the evidence base supporting the use of CBT and GET. Updated NICE guidance is planned for publication in 2020.

It is important to highlight that the current NICE CFS/ME guideline acknowledges that there is no one form of treatment to suit every patient and that treatment and care should take into account the personal needs and preferences of the patient. NICE also makes clear that, in common with all people receiving care in the National Health Service, those with CFS/ME have the right to refuse or withdraw from any component of their care plan.

**HL Deb 20 June 2018 | PQ HL8447**

### [Chronic Fatigue Syndrome](#)

**Asked by: Osamor, Kate**

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to raise awareness of myalgic encephalomyelitis among the public and medical practitioners.

**Answering member: Steve Brine | Department: Department of Health and Social Care**

There is information on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) for both healthcare professionals and the general public via the NHS Choices website. Further information is also provided in the National Institute for Health and Care Excellence (NICE) clinical guideline on CFS/ME, which is provided in formats suitable for both professionals and the public. Both the NHS Choices and NICE guidance can be found at the following links:

[www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/](http://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/)

[www.nice.org.uk/guidance/cg53](http://www.nice.org.uk/guidance/cg53)

Education and training is also an important feature in building the awareness of clinical professionals. In terms of education and training, the General Medical Council sets out the knowledge, skills and behaviours that new United Kingdom medical graduates must be able to demonstrate and Royal Medical Colleges, such as the Royal College of General Practitioners (RCGP), set the standards for postgraduate medical education in general practice. General practice is where most patients with CFS/ME are likely to be managed, and the condition is identified as a key area of clinical knowledge in the RCGP Applied Knowledge Test (AKT) content guide. The AKT is a summative assessment of the knowledge base that underpins general practice in the United Kingdom within the context of the National Health Service and is a key part of GPs' qualifying exams. In addition, the RCGP offers a free online e-learning course for clinicians which covers the diagnosis treatment and care of patients with CFS/ME.

Once fully qualified, clinicians are responsible for ensuring their own clinical knowledge remains up-to-date and for identifying learning needs as part of their continuing professional development. This activity should include taking account of new research and developments in guidance, such as that produced by NICE.

**HC Deb 11 June 2018 | PQ 148978**

### [Mental Health Services](#)

**Asked by: The Countess of Mar**

To ask Her Majesty's Government, further to the Written Answer by Lord O'Shaughnessy on 15 May (HL7468), upon what scientific evidence the promotion of cognitive behaviour therapy and graded exercise therapy in the Improving Access to Psychological Therapies programme is based; and what assessment they have made of recovery rates for

patients with myalgic encephalomyelitis or chronic fatigue syndrome from pilot programmes of such therapies.

**Answering member: Lord O'Shaughnessy | Department:  
Department of Health and Social Care**

The inclusion of these therapies is based on National Institute for Health and Care Excellence (NICE) guidance. NICE is the independent expert body responsible for developing robust, evidence based guidance for the National Health Service. In 2007, NICE published a guideline on the management of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in adults and children that sets out best practice on the treatment and support of patients. The guidance recommended cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as appropriate treatments for mild to moderate CFS/ME, in line with the best available evidence from eight randomised controlled trials. A copy of the guidance, *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management*, is attached.

Information concerning the assessment of recovery rates for patients with CFS/ME accessing CBT or GET through Improving Access to Psychological Therapies services is not available.

**HL Deb 05 June 2018 | PQ HL8135**

[Chronic Fatigue Syndrome](#)

**Asked by: Brennan, Kevin**

To ask the Secretary of State for Health and Social Care, what funding his Department has allocated to support research into treatment for myalgic encephalomyelitis in each of the last five years; and what plans he has to allocate further funding for such research.

**Answering member: Caroline Dinenage | Department:  
Department of Health and Social Care**

The following table shows information provided by the National Institute for Health Research (NIHR) on Departmental programme research funding for myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), over each of the last five years. It is not possible to disaggregate funding for research into treatments specifically but further information on this research is available through the NIHR Journals Library at the following link:

<https://www.journalslibrary.nihr.ac.uk/programmes/>

Financial Year £

2013-14	561,950
2014-15	426,055
2015-16	475,676
2016-17	554,785

2017-18 464,902

In terms of future research, the NIHR recognises that CFS/ME is a debilitating condition and is speaking with the UK CFS/ME Research Collaborative and patient representatives about how best to support a joined up approach to high quality research into this complex disorder. The NIHR welcomes funding applications for research into any aspect of human health, including CFS/ME; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

**HC Deb 04 June 2018 | PQ 147821**

[Chronic Fatigue Syndrome](#)

**Asked by: Monaghan, Carol**

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2010-2011.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2011-2012.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2012-2013.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2013-2014.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse he plans to allocate to biomedical research into Myalgic Encephalomyelitis in the current financial year.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into Myalgic Encephalomyelitis 2016-2017.

**Answering member: Caroline Dinenage | Department:  
Department of Health and Social Care**

In the period in question, the major National Institute for Health Research funding for biomedical research was through its Biomedical Research Centres (BRCs) and Units. These support research funded by the NIHR itself and also research funded by other public, charity and industry research funders. Prior to the financial year 2104-15, the way data was collected does not allow us to directly report the level of funding for biomedical research into chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Three BRCs were supporting biomedical research into CFS/ME during this time period.

The NIHR Clinical Research Network (CRN) provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be delivered throughout the National Health Service. The level of funding for biomedical research into CFS/ME for each financial year supported by the CRN can be found in the following table. The funding for this research came from a combination of the Medical Research Council (MRC) and medical research charities. Expenditure from the CRN itself is also outlined below:

Financial Year	Research funding £	CRN expenditure £
2010-11	0	0
2011-12	43,467	5,217
2012-13	114,349	13,616
2013-14	171,860	21,353

The MRC spend on research directly relating to CFS/ME can be found in the following table. The MRC does not classify research in the area by type and is therefore not able to include a further breakdown by type of project. Research into CFS/ME is a continuing priority for the MRC.

Financial Year	£
2010-11	0
2011-12	0
2012-13	504,194
2013-14	601,509

The NIHR and the MRC welcome funding applications for research into any aspect of human health, including biomedical research into CFS/ME. It is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

The NIHR recognises that CFS/ME is a debilitating condition and is speaking with the United Kingdom CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

**HC Deb 24 May 2018 | PQ 146299; PQ 146298; PQ146297;  
PQ146296; PQ 145347; PQ 145356; PQ 145355**

## 7. Useful links

ME Association, [Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis](#), January 2019

NHS Choices *Chronic fatigue syndrome (CFS/ME)*

<https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/>

National Academies of Science, Engineering and Medicine *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness* 10 February 2015

<http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>

2020 Health The Optimum Health Clinic Foundation *Counting the Cost: CFS/ME* 28 September 2017

<http://www.2020health.org/2020health/Publications/Publications-2017/OHC.html>

ME Association *M.E. Research Conference Report: London* 1st June 2018 13th Invest in ME Research (liMER) Conference

<http://www.meassociation.org.uk/wp-content/uploads/Dr-Shepherd-liMER-Conference-Report-2018-13.06.18.pdf>

Cochrane evidence review *Exercise as treatment for patients with chronic fatigue syndrome* 25 April 2017

[http://www.cochrane.org/CD003200/DEPRESSN\\_exercise-treatment-patients-chronic-fatigue-syndrome](http://www.cochrane.org/CD003200/DEPRESSN_exercise-treatment-patients-chronic-fatigue-syndrome)

Royal College of Psychiatrists Mental Health and Growing Up Factsheet *Chronic Fatigue Syndrome (CFS) - helping your child to get better: information for parents, carers and anyone who works with young people*

<https://www.rcpsych.ac.uk/healthadvice/parentsandyoungpeople/parent-scarers/chronicfatiguesyndrome.aspx>

ME Research UK

<http://www.mereseearch.org.uk/what-is-me/>

ME Association

<https://www.meassociation.org.uk/>

Action for M.E.

<https://www.actionforme.org.uk/>

Forward-M.E.

<http://www.forward-me.org.uk/>

Scottish Government National Advisory Committee for Neurological  
Conditions

<https://www.gov.scot/groups/national-advisory-committee-for-neurological-conditions/>



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