

To: Dr. Beth Unger and Dr. Jennifer McQuiston  
CC: Dr. Inger Damon, Dr. Susan Levine, Gustavo Seinos  
Date: November 30, 2016  
Subject: ME/CFS treatment recommendations and disease statements on CDC's website

We are contacting you regarding CDC's continued inclusion of scientifically indefensible recommendations for cognitive behavioral therapy (CBT) and graded exercise therapy (GET) along with unfounded statements about the nature of ME/CFS on its website. Advocates have repeatedly raised these issues with CDC over the years, most recently in September 2016. CDC has long defended the inclusion of this harmful information while more recently stating that it would consider some of these concerns in future website revisions. However, CDC has explicitly stated that its current efforts will not address these issues and has given no date by which it will address them. Therefore, we are contacting you again to ask when CDC intends to correct these problems.

Previously, advocates have provided CDC evidence on these issues that included Dr. David Tuller's analysis of the grave problems with the PACE trial,<sup>1</sup> the non-specificity of the Oxford definition, the downgrading of recommendations for CBT and GET by the AHRQ Addendum once Oxford studies were excluded,<sup>2</sup> and the surveys done by patient organizations demonstrating that these therapies result in harm to patients.<sup>3</sup> Tuller's most recent investigative report, *Worse than the Disease*, published in MIT's Undark magazine, exposes the deleterious impact of PACE and similar trials on mainstream clinical guidelines in the U.S. as well as the terrible price paid by one ME/CFS patient - Nita Thatcher - as a result of these treatments and the underlying psychogenic disease theory.<sup>4</sup> Nita's story is deeply painful to read, made more so by knowing that her story has been replicated many times over in the U.S. and around the world.

In addition to telling Nita's personal story, Tuller draws an undeniable line of sight from the use of unscientific disease definitions and the misconduct of the PACE trial to the adoption of mainstream clinical guidance based on these scientifically flawed studies and from there to the unforgivable harm that patients like Nita have experienced at the hands of their doctors. As detailed further below, the issues include:

1. **PACE study conduct:** Tuller and others have demonstrated flagrant problems with the study conduct and the findings of the U.K. PACE trial, the flagship trial upon which current clinical recommendations for CBT and GET have often been based. Recent analysis has demonstrated that PACE's inflated claims of efficacy almost disappeared when data was reanalyzed according to the trial's original protocol.
2. **Inaccurate disease definition:** Studies of CBT, GET, and psychogenic factors in disease pathology, predisposition, and perpetuation have used the overly broad Oxford definition. But recent U.S. government reports noted the Oxford definition includes patients who do not have ME/CFS and called for Oxford to be retired.<sup>5</sup> Further, the 2016 AHRQ Evidence Review Addendum showed a lack of effectiveness of CBT and GET once these Oxford studies were excluded from analysis. Pointedly, these recommendations for CBT and GET and statements claiming that psychogenic factors are driving the disease have been based on studies of people who do not actually have the disease.
3. **Scientifically invalid disease theory:** The studies of CBT, GET and psychogenic factors in disease risk and prognosis were based on a disease theory that claimed that the debility of the disease was driven by a fear of activity and deconditioning reversible by CBT and GET. This disease theory is in direct conflict with the organic disease described by the 2015 National

Academy of Medicine (NAM) report, the breadth of published biomedical research, and the positive effect achieved by drugs such as Rituxan and Ampligen.

4. **Harm done to patients:** The harms experienced by patients subjected to CBT and GET have been widely documented in patient surveys and anecdotal patient reports. Such harms are predictable given the systemic intolerance to exertion that the 2015 NAM report defined as the hallmark of the disease, yet harms have been largely ignored in mainstream clinical guidance.

The 2015 National Academy of Medicine report highlighted the medical community's hostility toward this disease and noted that the biggest challenge to moving forward is not medical provider knowledge but rather medical provider attitudes. Yet, providing indefensible reasons for doing so as outlined below, CDC still includes recommendations for CBT and GET and psychogenic disease statements and references on its website. Other medical education providers and medical centers do the same with some referencing CDC's recommendations as their justification for doing so. Such content has created a false narrative about the disease, which fosters those negative attitudes and creates a risk of physical harm for patients. If this were a drug, the FDA would shut it down.

As our country's premier health organization, CDC must provide the ethical and proactive leadership needed to decisively break away from this painful and decades-long legacy of disbelief, mistreatment, and harm that Tuller's *Worse than the Disease* so comprehensively explained. A first step must include removal of all recommendations for CBT and GET and the removal of information based on Oxford and the psychogenic disease theory (as on CDC's Science Clips)<sup>6</sup> and replacement with content such as that provided in the 2014 IACFS/ME primer<sup>7</sup> and 2012 ME-ICC primer,<sup>8</sup> both authored by disease experts. Beyond that, CDC must proactively reach out to medical education providers like UpToDate, medical societies such as the American College of Family Physicians, and medical centers such as Mayo and the Cleveland Clinic to ensure that these groups also appreciate that these therapies and psychogenic narratives are wrong.

CDC has the responsibility to ensure that it provides accurate information and protects the lives of patients. The continued inclusion of these recommendations, statements and references on CDC's website is neither medically ethical nor scientifically defensible. We understand that CDC is currently updating its website but that work will not address these issues. To protect patients, it is essential that these concerns be addressed immediately. Accordingly, we are asking for a date in the very near future by which CDC will remove the above referenced content from its website. We respectfully request a response by December 20, 2016.

Sincerely,

#### **Patient Organizations**

Massachusetts CFIDS/ME & FM Association	Phoenix Rising
MEAdvocacy.Org	Race to Solve ME/CFS
New Jersey ME/CFS Association, Inc.	Solve MECFS Initiative
Northern Virginia CFSupport	Speak Up About ME
Open Medicine Foundation	Wisconsin ME and CFS Association, Inc.
Pandora Org	

#### **Patients, Patient Carers, and Patient Advocates**

Bobbi Ausubel, MFA, RDT (CA)	Wilhelmina D. Jenkins (GA)
Jessica Belkov Gordon (GA)	Raquel Johnson (CA)

Diane, James and Lauren Bean (MD)  
David Bergstrom (CA)  
Kristin Bergstrom, RN (CA)  
Katie Bergstrom (CA)  
Virginia Bergstrom (CA)  
Andrew Bergstrom (CA)  
Carol Broadbent (CA)  
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Mark Camenzind, PhD (CA)  
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Drew Higginson (CA)  
Grant Hodgson (NJ)  
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Dave Johnson (CA)  
Roslyn Leiser, RN (CA)  
Denise Lopez-Majano, (PA)  
Timbre Livesay, MFT (GA)  
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Billie Moore (NJ)  
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Jane B Pannell, RN, ACRN (CA)  
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Greg Polchow (CA)  
Mary Prior, R.N., (BSN), M.Ed. (GA)  
Mark C Shaw (CA)  
Jennifer M. Spotila, JD (PA)  
Mary Ellen Strand, MSN, RN, APRN (WI)  
Diane Tarshis (IL)  
Jay Tarshis (IL)  
Adriane Tillman (CA)  
Julia Thomas, RN, MSN, NP (CA)  
Sarah Turner (VA)  
Loetta Vann (MD)  
Erica Verillo (MA)  
Debra Walter RN, NP (CA)  
Kellyann Wargo (TX)  
Wayne Wichern (WA)

## **Background** *(Additional supporting references or background available on request)*

The following summarizes the evidence supporting this call for CDC to remove recommendations for CBT and GET and statements based on Oxford studies and a psychogenic disease theory from its medical education information for ME/CFS.

### **1. Flawed Definition used in Studies of CBT, GET, and Psychogenic Risk/Prognosis Factors**

Many of the CBT and GET studies used the 1991 Oxford definition, which only requires 6 months of chronic fatigue and no other symptoms while allowing the inclusion of mental disorders. The 2014 AHRQ Evidence Review stated that the use of the Oxford definition "results in a high risk of including patients [in studies] who may have an alternate fatiguing illness or whose illness resolves spontaneously with time."<sup>9</sup> That review and NIH's 2015 Pathways to Prevention (P2P) Workshop report<sup>10</sup> called for Oxford to be retired, with P2P stating Oxford could "impair progress and cause harm."

Because of concerns with Oxford's lack of specificity, AHRQ reanalyzed the evidence for CBT and GET and issued an Addendum to its evidence review in 2015. That Addendum reported insufficient evidence for GET and barely any evidence for CBT *once Oxford studies were excluded*. The Addendum also noted that CBT and GET had not been studied using disease definitions requiring post-exertional malaise or other criteria considered mandatory by the 2015 NAM report, further demonstrating the lack of evidence for these therapies specifically in ME/CFS.

Beyond treatments, studies using Oxford have claimed that patients' behavior, personality, and beliefs are responsible for or contribute to disease pathology, predisposition, and perpetuation. Two of these studies were posted on CDC's Science Clips in February 2016.<sup>11</sup> The Afari article claims that "patients' perceptions, attributions, and coping skills...may help perpetuate the illness" and that patients' "perceptions" of difficulty contribute to their negative reaction to exertion. Afari recommends CBT and GET based on "research suggesting that cognitive and behavioral factors play a role in perpetuating the symptoms of chronic fatigue syndrome." The referenced research included Oxford studies and studies performed by those later involved in PACE. The Crawley article on Science Clips is based solely on parent-reported chronic fatigue (not CFS) and did not include a diagnosis by a doctor. This is not ME/CFS yet this evidence is then used to claim that family adversity and maternal psychopathology are risk factors in this disease.

### **2. Flagship Study of CBT and GET Flawed**

In October 2015, Dr. Tuller published an analysis of the flagship 2011, £5 million PACE trial of CBT and GET, in which he highlighted serious concerns with study conduct, including outcome switching and the redefinition of recovery.<sup>12</sup> Rebecca Goldin, a Professor of Mathematical Sciences at George Mason University, subsequently reassessed PACE conduct and confirmed Tuller's concerns.<sup>13</sup> In September 2016, PACE data was released following a successful appeal of a FOIA request and was independently analyzed according to the parameters defined in the original trial protocol instead of the modified methods adopted by PACE after the trial began. As reported on Dr. Racaniello's Virology Blog,<sup>14</sup> in Stat News,<sup>15</sup> and most recently in the Journal of Health Psychology,<sup>16</sup> this reanalysis showed that, compared to PACE's claim of a 22% recovery rate, there was no evidence that patients recover following CBT or GET. Further, PACE's previously reported claim of 60% improvement dropped to 10% upon reanalysis. And of course, given that PACE used the discredited Oxford criteria, the relevance of any improvements to patients with ME/CFS must be questioned.

Unfortunately, these inflated claims of treatment effectiveness and the unsupportable claim that the results of the trial and earlier trials applied to ME/CFS patients have been broadly disseminated by the media and in scientific evidence reviews. As a result, recommendations for CBT and GET are

now widespread across mainstream "evidence-based" clinical guidance for ME/CFS, including those from CDC as well as UpToDate, Mayo, Kaiser Permanente and others. These sources often directly reference PACE to support these recommendations,<sup>17</sup> something that CDC also did in one of its CMEs until the summer of 2016.<sup>18</sup>

The uptake of recommendations for PACE-style CBT and GET is not limited to medical education providers. Medical societies such as the American Academy of Family Physicians have included information based on PACE and related studies in their clinical guidance<sup>19</sup> and in a 2016 training needs assessment.<sup>20</sup>

### **3. Patient Surveys Demonstrating Harm from CBT and GET**

Patient surveys have repeatedly reported harm from CBT and GET. A 2011 review of eight GET surveys and five CBT surveys found that 51 percent of survey respondents reported that GET worsened their health while 20 percent said that CBT worsened their health. One survey in severely ill patients reported that 82 percent of respondents experienced harm due to GET.<sup>21</sup> A 2014 survey of 1428 patients conducted by U.K.'s ME Association also reported adverse reactions to GET and CBT.<sup>22</sup> The harms reported in these surveys are backed up by innumerable anecdotal patient reports, including those made directly to CDC at many CFSAC meetings over the years. Tuller's article adds to this evidence with a deep case study of one patient's adverse experience.

Notably, investigators of CBT and GET have stated that CBT and GET do not cause harm to patients. This is a surprising claim, given that the 2015 NAM report noted a systemic intolerance to exertion. The reality, as noted by the AHRQ Evidence Review, is that these studies had underreported harms and compliance. The claims that CBT and GET do not harm ME/CFS patients have no factual basis, as the harms experienced by patients were not reported and the patients studied included patients with other conditions.

One suggestion has been to change the name from "graded exercise therapy" to "activity management." However, this alone is not sufficient, as that term has already been stamped in the U.K. as referring to a graded increase in activity, with one study calling for a 10-20% increase in activity each week.<sup>23</sup>

### **4. Scientifically Invalid Disease Theory Underlying These Studies**

The use of CBT and GET in CFS and its evidence base are based on the biopsychosocial (BPS) disease theory in which the debility of CFS is caused by deconditioning, which in turn is purported to be the result of a fear of activity and false cognitions of illness. CBT and GET are claimed to result in recovery by reversing the patient's fear of activity, false cognitions, and deconditioning. As seen in the Afari and Crawley articles on CDC's Science Clips website, the BPS theory also claims that risk factors include personality flaws and that poor prognosis can result simply from a patient *thinking* they have an organic illness. (UpToDate has included this prognosis claim in its clinical guidance.<sup>24</sup>)

In sharp contrast, the 2015 AHRQ Addendum stated that the CBT had a "disputable underlying rationale regarding the fear avoidance theory contributing to the perpetuation of symptoms in ME/CFS." The 2015 National Academy of Medicine Report definitively stated that ME/CFS is not a psychological problem. Dr. Ellen Clayton, NAM panel chair, and Dr. Peter Rowe, panel member, also roundly dismissed the idea that the debility of ME/CFS could be the result of deconditioning.<sup>25</sup> Instead, the NAM report provided a broad cross-section of biomedical evidence and decisively noted that ME/CFS is characterized by a systemic exacerbation of all symptoms following even trivial activity that is accompanied by a range of abnormal physiological responses. As demonstrated at the 2016 IACFS/ME conference, numerous studies have confirmed and extended

these findings, demonstrating widespread energy production, neurological, autonomic, and immunological impairment.<sup>26</sup>

### **5. CDC's Rationale for Continuing to Include This Information is Scientifically Indefensible**

Over many years, advocates have contacted CDC to raise concerns with CDC's recommendations for CBT and GET and statements based on Oxford studies and a psychogenic disease theory. With the recent articles from Tuller and others on the PACE trial as evidence, advocates again contacted CDC on November 15, 2015 to convey these issues and ask that statements based on these studies be removed from CDC's website.<sup>27</sup> CDC's responses over the last year have not addressed these concerns. In a recent teleconference and follow up emails with advocates, CDC defended the inclusion of CBT and GET recommendations with the claim that PACE also used the Fukuda definition. PACE had used a significantly altered Fukuda, which it acknowledged would impact patient selection.<sup>28</sup> But ultimately this didn't matter since the recent PACE reanalysis has demonstrated the claims of effectiveness were overblown, regardless of the definition used.

CDC has also defended these recommendations with the statement that CDC intends them as management tools, not treatments and not as practiced in PACE. However, CDC has acknowledged that the terms "CBT" and "GET" are tainted. These terms are tainted as they have been stamped with the false illness/deconditioning narrative. Referring to CBT and GET as management tools instead of treatments does not compensate for that fact. In addition, while CDC may not intend PACE-style CBT and GET, CDC's lack of precision on its website regarding the intended approach, expected benefit, contra-indications, and potential harm of its recommendations leaves medical providers vulnerable to believing that the broadly disseminated claims for PACE-style CBT and GET are correct. More critically, while CDC has stated that these recommendations help some unspecified group of patients, CDC's recommendations as currently stated place ME/CFS patients *at all levels of severity* at risk of physical harm. Admittedly, deconditioning will be a problem in any chronic disease that limits a patient's activity. But given the systemic intolerance to exertion at the heart of this disease, it is essential that any recommendations for activity be given with the same care required for drugs.

CDC also defended the continued inclusion of harmful references posted on CDC's Science Clips site to support CDC's 2016 CFS Grand Rounds. This includes articles by Afari and Crawley that are largely based on Oxford studies and a psychogenic view of the disease. In an August teleconference with two advocates, CDC defended these articles with the statement that doctors are smart people and can sift through bad information. But as Tuller's *Worse than the Disease* clearly demonstrates, doctors cannot do that nor should they be expected to.

CDC has said that they will remove the term "graded exercise therapy" at some future date but has not said what it intends to do about the remainder of these issues or when this will be done. In the face of all this evidence, the CDC must reevaluate the medical ethicality and scientific validity of continuing to include information that promotes this psychogenic disease theory, particularly as it prepares to roll out diagnostic criteria.

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<sup>1</sup> Tuller, D. "TRIAL BY ERROR: The Troubling Case of the PACE Chronic Fatigue Syndrome Study." *Virology Blog*. October 21-23, 2015.

- First installment: <http://www.virology.ws/2015/10/21/trial-by-error-i/>
- Second installment: <http://www.virology.ws/2015/10/22/trial-by-error-ii/>
- Third installment: <http://www.virology.ws/2015/10/23/trial-by-error-iii/>

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- <sup>2</sup> U.S. Agency for Healthcare Quality and Research. "Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." Evidence Report/Technology Assessment Number 219. U.S. Agency for Healthcare Quality and Research. December 9, 2014. Updated July 28, 2016. AHRQ Pub. No. 15-E001-EF <https://effectivehealthcare.ahrq.gov/ehc/products/586/2004/chronic-fatigue-report-160728.pdf>
- <sup>3</sup> Kindlon T. "Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." *Bulletin of the IACFS/ME* Fall 2011; 19(2):59-111. <http://web.archive.org/web/20130115105558/http://www.iacfsme.org/BULLETINFALL2011/Fall2011KindlonHarmsPaperABSTRACT/tabid/501/Default.aspx>
- <sup>4</sup> Tuller, D. "Worse than the Disease." *UnDark*. October 27, 2016. <http://undark.org/article/chronic-fatigue-graded-exercise-pace/>
- <sup>5</sup> U.S. Agency for Healthcare Quality and Research. "Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." Evidence Report/Technology Assessment Number 219. U.S. Agency for Healthcare Quality and Research. December 9, 2014. Updated July 28, 2016. AHRQ Pub. No. 15-E001-EF <https://effectivehealthcare.ahrq.gov/ehc/products/586/2004/chronic-fatigue-report-160728.pdf>
- <sup>5</sup> National Institute of Health. Office of Disease Prevention. "Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. December 9-10, 2014. Executive Summary." National Institute of Health. Office of Disease Prevention. Final Report issued on June 16, 2015. <https://prevention.nih.gov/docs/programs/mecfs/ODP-P2P-MECFS-FinalReport.pdf>
- <sup>6</sup> CDC Science Clips, Volume 8, Issue 7, February 16, 2016 <https://www.cdc.gov/library/sciclips/issues/v8issue7.html>  
Examples include articles by Afari and Crawley referenced below.
- <sup>7</sup> *International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis*. "Chronic Fatigue Syndrome Myalgic Encephalomyelitis: A Primer for Clinical Practitioners 2014 Edition." *International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis*. 2012, revised 2014. <http://www.iacfsme.org/LinkClick.aspx?fileticket=iD3JkZAZhts%3d&tabid=509>
- <sup>8</sup> Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T, Staines D, Powles ACP, Speight N, Vallings R, Bateman L, Bell DS, Carlo-Stella N, Chia J, Darragh A, Gerken A, Jo D, Lewis D, Light AR, Light K, Marshall-Gradisnik S, McLaren-Howard J, Mena I, Miwa K, Murovska M, Steven S. "Myalgic Encephalomyelitis – Adult and Paediatric: International Consensus Primer for Medical Practitioners." Co-editors B.M. Carruthers and M.I. van de Sande. Published by Carruthers and van de Sande, 2012. [http://www.hetalternatief.org/ICC\\_primer\\_2012.pdf](http://www.hetalternatief.org/ICC_primer_2012.pdf)
- <sup>9</sup> U.S. Agency for Healthcare Quality and Research. "Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." Evidence Report/Technology Assessment Number 219. U.S. Agency for Healthcare Quality and Research. December 9, 2014. Updated July 28, 2016. AHRQ Pub. No. 15-E001-EF <https://effectivehealthcare.ahrq.gov/ehc/products/586/2004/chronic-fatigue-report-160728.pdf>
- <sup>10</sup> National Institute of Health. Office of Disease Prevention. "Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. December 9-10, 2014. Executive Summary." National Institute of Health. Office of Disease Prevention. Final Report issued on June 16, 2015. <https://prevention.nih.gov/docs/programs/mecfs/ODP-P2P-MECFS-FinalReport.pdf>
- <sup>11</sup> CDC Science Clips, Volume 8, Issue 7, February 16, 2016 <https://www.cdc.gov/library/sciclips/issues/v8issue7.html>  
Examples include these two articles:
- Afari N, Buchwald D. "Chronic fatigue syndrome: a review." *Am J Psychiatry*. February 2003; 160(2):221-36. <http://www.ncbi.nlm.nih.gov/pubmed/12562565>
  - Crawley E. "The epidemiology of chronic fatigue syndrome/myalgic encephalitis in children." *Arch Dis Child*. Published Online October 21, 2013; <http://adc.bmj.com/content/early/2013/10/21/archdischild-2012-302156.abstract>
- <sup>12</sup> Tuller, D. "TRIAL BY ERROR: The Troubling Case of the PACE Chronic Fatigue Syndrome Study." *Virology Blog*. October 21-23, 2015. <http://www.virology.ws/2015/10/21/trial-by-error-i/>
- <sup>13</sup> Goldin, Rebecca. "PACE: The research that sparked a patient rebellion and challenged medicine." *Stats.Org*. March 21, 2016. <http://www.stats.org/pace-research-sparked-patient-rebellion-challenged-medicine/>

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- Also see: Butterworth, T. "Editorial: On PACE." *Stats.Org*. March 21, 2016. <http://www.stats.org/editorial-on-pace/>
- <sup>14</sup> "No 'Recovery' in PACE Trial, New Analysis Finds." *Virology Blog*. September 21, 2016. <http://www.virology.ws/2016/09/21/no-recovery-in-pace-trial-new-analysis-finds/>
- <sup>15</sup> Rehmeyer, J. "Bad science misled millions with chronic fatigue syndrome. Here's how we fought back." *Stat News*. September 21, 2016. <https://www.statnews.com/2016/09/21/chronic-fatigue-syndrome-pace-trial/>
- <sup>16</sup> Geraghty, K. "'PACE-Gate': When clinical trial evidence meets open data access." *J Health Psychol* November 1, 2016. <http://hpq.sagepub.com/content/early/2016/10/27/1359105316675213.full.pdf.html>
- <sup>17</sup> Gluckman, Stephen. "Treatment of chronic fatigue syndrome (systemic exertion intolerance disease)" *UpToDate*. Deputy Editor Lee, P. Last updated November 16, 2015. Literature Review current through December 2015. Accessed January 2016. [http://www.uptodate.com/contents/treatment-of-chronic-fatigue-syndrome-systemic-exertion-intolerance-disease?source=see\\_link](http://www.uptodate.com/contents/treatment-of-chronic-fatigue-syndrome-systemic-exertion-intolerance-disease?source=see_link)  
As of November 16, 2016, the site still cites PACE
- <sup>18</sup> CDC's CME for diagnosis and management, removed the summer of 2016, used PACE along with similar studies to support its recommendations for management. See reference #26.  
U.S. Centers for Disease Control and Prevention. "Diagnosis and Management of Chronic Fatigue Syndrome" *CDC Chronic Fatigue Syndrome*. CME created: June 27, 2012. Page last updated: May 16, 2014. Page removed from CDC's site in summer of 2016.  
<https://web.archive.org/web/20160513031126/http://www.cdc.gov/cfs/education/diagnosis/course.html>
- <sup>19</sup> Yancey J, Thomas S. "Chronic Fatigue Syndrome: Diagnosis and Treatment." *American Family Physician* October 15, 2012; 86(8):741-746. PMID: 23062157 <http://www.aafp.org/afp/2012/1015/p741.html>
- <sup>20</sup> Yancey J, Thomas S. "Chronic Fatigue Syndrome: Diagnosis and Treatment." *American Family Physician* October 15, 2012; 86(8):741-746. PMID: 23062157 <http://www.aafp.org/afp/2012/1015/p741.html>  
Also see the 2016 AAFP training needs assessment  
<http://www.aafp.org/dam/AAFP/documents/events/fmx/needs/muscu-systemic-exertion-intolerance-disease.pdf>
- <sup>21</sup> Kindlon T. "Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." *Bulletin of the IACFS/ME* Fall 2011; 19(2):59-111.  
<http://web.archive.org/web/20130115105558/http://www.iacfsme.org/BULLETINFALL2011/Fall2011KindlonHarmsPaperABSTRACT/tabid/501/Default.aspx>
- <sup>22</sup> ME Association. "ME/CFS Illness Management Survey Results 'No decisions about me without me.'" *MEAssociation*. May 2015. <http://www.meassociation.org.uk/2015/05/23959/>
- <sup>23</sup> Crawley, E. et al. "Investigating the effectiveness and cost-effectiveness of using FITNET-NHS (Fatigue In Teenagers on the interNET in the NHS) compared to Activity Management to treat paediatric Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) in the United Kingdom: A randomised controlled trial (FITNET-NHS)" *University of Bristol*. October 10, 2016.  
[http://www.nets.nihr.ac.uk/\\_data/assets/pdf\\_file/0007/170962/PRO-14-192-109.pdf](http://www.nets.nihr.ac.uk/_data/assets/pdf_file/0007/170962/PRO-14-192-109.pdf)  
This protocol calls for patients to set a baseline and then increase their activity by 10-20% each week.
- <sup>24</sup> Gluckman, Stephen. "Treatment of chronic fatigue syndrome (systemic exertion intolerance disease)" *UpToDate*. Deputy Editor Lee, P. Last updated November 16, 2015. Literature Review current through December 2015. Accessed January 2016. [http://www.uptodate.com/contents/treatment-of-chronic-fatigue-syndrome-systemic-exertion-intolerance-disease?source=see\\_link](http://www.uptodate.com/contents/treatment-of-chronic-fatigue-syndrome-systemic-exertion-intolerance-disease?source=see_link)
- <sup>25</sup> Tucker, M. "IOM Gives Chronic Fatigue Syndrome a New Name and Definition." *Medscape Medical News*. February 10, 2015. <http://www.medscape.com/viewarticle/839532>
- <sup>26</sup> Vallings, Ros. Summary of the 12<sup>th</sup> IACFSME Conference. October 27-30, 2016 – Fort Lauderdale, USA  
<https://dl.dropboxusercontent.com/u/89158245/Vallings%20Summary%2012th%20IACFSME%20CONFERENCE%202016.docx>
- <sup>27</sup> Community letter to Dr. Thomas Frieden and Dr. Richard Kronick requesting that AHRQ and CDC address concerns raised by Dr. David Tuller. November 15, 2015.  
<https://dl.dropboxusercontent.com/u/89158245/CDC-AHRQ%20Request%20PACE%20Nov%202015.pdf>

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Response from Dr. Inger Damon to the community letter. December 23, 2015.

<https://dl.dropboxusercontent.com/u/89158245/CDC%20Response%20to%20PACE%20request%20-%20Dec%2023%202015.pdf>

<sup>28</sup> The PACE trial modified Fukuda to only require one week of symptoms instead of 6 months. The PACE study publication itself acknowledged that this could have affected the identification of patients.

- White PD, Goldsmith K, Johnson AL, Chalder T, Sharpe M, PACE Trial Management Group. "Recovery from chronic fatigue syndrome after treatments given in the PACE trial." *Psychol Med*. October 2013; 43(10): 2226-2235. PMID: 23363640. <http://dx.doi.org/10.1017/S0033291713000020>