

A Position Paper in Support of the CFSAC Recommendations on the Toolkit and Primer

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Submitted by

ME/CFS Patient Organizations

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Summary of the Recommendation

On June 14, 2012, the CFS Advisory Committee (CFSAC) formally recommended that the CDC CFS Toolkit (1) be removed from the CDC CFS site and that the International Association for CFS/ME (IACFS/ME) Primer for Clinical Practitioners (2) be made widely available to primary care physicians.

It is our position that expeditious execution of both of these recommendations is crucial in order to improve the quality of medical care available to ME/CFS patients. Furthermore, this represents an essential step towards reducing the misinformation, misunderstanding, disbelief and stigma that exists in the medical community.

The CDC has stated that the Toolkit plays a different role than the Primer as it “is intended as an introduction to CFS” (3) and that the Toolkit “has been effective in raising awareness and in encouraging a dialogue between health care providers and patients.” (3) But almost every patient tells of a very different story of misunderstanding and disbelief; a story reinforced by ME/CFS clinicians.

Regardless of the Toolkit’s intended purpose and stated claims, our position is that the Toolkit contains fundamental flaws in how ME/CFS is presented and is seriously *miseducating* medical providers about the nature of ME/CFS and about appropriate diagnostics and treatments. This miseducation has resulted in medical and public confusion as well as the stigma and harmful recommendations that patients receive. Removing the current Toolkit is essential to patient care.

In contrast to the Toolkit, Steve Krafchick, CFSAC member stated the IACFS/ME Primer is “a good, basic document that gives a primary care physician a real road map, whether it is to consider a differential diagnosis or different treatment options. There’s nothing like it anywhere else”. (4)

Making the Primer available through the National Guidelines Clearinghouse is a good first step. But doctors, patients, secondary medical information providers, medical clinics and others look directly to the CDC CFS website for information on ME/CFS. It is essential that they can easily and directly access the highest quality information available. There is precedent for linking to external information in other disease areas and on the CDC CFS website itself. (5) We urge the CDC to work with the IACFS/ME to do something similar for ME/CFS.

If the Toolkit-style document is needed to provide an introduction to ME/CFS, we encourage the CDC to work with the IACFS/ME to adapt the high quality content of the Primer into a new Toolkit that meets the CDC’s stated goal of providing an easy to use guide for physicians. We request and recommend that this new Toolkit be made available through the CDC website no later than January 2, 2013.

For the sake of ME/CFS patients, especially new patients who are desperately trying to understand what is wrong, these recommendations must be implemented as soon as possible to ensure that medical practitioners can effectively care for patients and that patients are not subjected to continued harm.

Finally, it cannot be overstated that other parts of the CDC CFS website and resources suffer from exactly the same information quality issues as the Toolkit itself. The CDC has an opportunity to leverage the high quality content of the Primer to improve other areas of the CDC website. We encourage the CDC to take advantage of this opportunity.

Background

Chronic fatigue syndrome, as defined by the 1994 Fukuda definition (6) requires fatigue for 6 months plus 4 of 8 other symptoms. This definition allows for a broad range of conditions that can cause fatigue, ranging from depression to the complex neuro-immune disease, referred to in this paper as ME/CFS and best described by the 2003 ME/CFS Canadian Consensus Criteria (CCC) or the 2011 ME-International Consensus Criteria (ME-ICC).

The Toolkit states that it “provides the best practices for diagnosing, treating and managing CFS.” However, Fukuda CFS is such a broad umbrella of fatiguing illnesses that it is not reasonable to expect a single clinical guidance document to provide meaningful, effective diagnostic and treatment guidance. The utility of the Toolkit and the Primer need to be assessed for how well they help providers deal with a specific disease. The analysis and recommendations in this paper pertain to the utility of the Toolkit and the Primer as clinical guidance for ME/CFS, not the broad range of fatiguing illnesses created by the Fukuda criteria.

ME/CFS affects an estimated one million Americans (7) leaving patients very ill, sometimes for decades, with an estimated twenty-five percent homebound or bedbound, unable to work. Patients experience profound exhaustion, sleep disorder, dizziness, orthostatic intolerance, neurological changes, cognitive problems (such as difficulty thinking, processing, and remembering), joint and muscle pain and also flu-like symptoms (such as swollen, tender lymph nodes, sore throat, and fever). Patients experience a worsening of many symptoms, called post-exertional malaise (PEM, also called post-exertional neuroimmune exhaustion or PENE) following even limited mental or physical activity. (8,9,10)

The CDC has said ME/CFS “can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease... and similar chronic conditions.” (11) Based on one retrospective study, patients are more likely to die prematurely from cancer, heart failure or suicide. (12) Compounding the personal devastation is the effect on our country’s economic well-being. ME/CFS costs our country an estimated \$18 - \$23 billion annually in medical costs and lost productivity. (13)

In spite of the tremendous impact to the individual and to our country, the medical community misunderstands the disease, is ill-prepared to care for the ME/CFS patient, and/or does not believe that the patient is really sick. (14,15,16,17,18) Every patient tells stories of doctors who told them they were depressed, dismissed their illness as made up, refused to treat them or recommended treatments that were inappropriate or harmful for ME/CFS patients. The sheer prevalence of these stories is evidence enough that there is a serious issue. Reinforcing this patient experience, Dr. Montoya has said, “it is my dream that our medical community will produce a formal apology to patients for not having believed them all these years that they were facing a real illness.” (15) Dr. Klimas, in March 2009 stated “I’ve had patients who met post-traumatic stress disorder criteria... where their trauma was their interaction with their physician around this illness. They came to a doctor with Chronic Fatigue Syndrome; they left the doctor with PTSD.” (16)

Unfortunately, even when doctors believe that something is seriously wrong, they often lack appropriate knowledge about how to diagnose and treat the illness, leaving patients without access to adequate medical care. Although there is no cure or treatment that addresses the root causes of ME/CFS yet, there are effective pharmacological and non-pharmacological treatments (such as pacing) that have not been fully exploited by healthcare providers to help patients manage their symptoms and illness. Patients’ care and quality of life have undoubtedly been negatively impacted as the result of an uninformed or misinformed medical community. (17,18)

Recommendations

We acknowledge the recent positive changes that the CDC has made to the CFS web site. But in spite of these changes, there are still serious and unacceptable flaws in the content of the CDC CFS Toolkit that are directly impeding clinician understanding of the disease and deleteriously affecting the quality of patient care.

Therefore, the following recommendations are made to address these flaws and thereby improve patient care. The rationale is provided in the 'Rationale' section below.

- 1. Immediately remove the CDC CFS Toolkit**

Whatever the CDC's intended purpose, the Toolkit's few and general recommendations can only lead physicians to downplay the seriousness of this disease and to use an approach that fails to attend to the health needs of the patient while potentially exposing them to real harm. For that reason, continued use of either the online or hardcopy version of the Toolkit is unacceptable.

- 2. Make the IACFS/ME Primer directly and easily available to primary care physicians and other key users from the CDC CFS website.**

It is good that the Primer will be available through the National Guidelines Clearinghouse. But this is just a first step. Doctors, patients, secondary medical information sources, insurance companies, public health departments, universities and medical clinics look to the CDC CFS website for information on ME/CFS. It is essential that all of these groups can easily and directly access the highest quality information available directly from the CDC CFS website.

This option of directly linking externally developed content like the Primer into the CDC CFS website was ruled out at the June 2012 CFSAC meeting and in follow-up correspondence with Dr. Belay. (3) But it is clear that this has been done for other disease areas; specifically the CDC sites for Fibromyalgia, (5) Epilepsy (5) and Hemochromatosis (5), all of which have prominent links to external sites that provide clinical guidelines (at least one with funding from pharmaceutical companies) or are patient advocacy organizations. In fact, the CDC CFS Toolkit itself links to external content – the GET guide from St. Bartholomew's. (1)

Given that such linking has been allowed on the CDC site at large and the CDC CFS site specifically, we urge the CDC and the IACFS/ME to work together to take the steps needed to link the IACFS/ME Primer into the CDC CFS website at least at the following pages: "Information for Healthcare professionals", "General Information/Diagnosis/For Doctors: Criteria for Diagnosing CFS" and "General Information/Management/Options for Treating and Managing CFS"

- 3. Work with the IACFS/ME to create an abbreviated versions of the Primer if needed**

Finally, if a shorter document is needed to provide an introduction to ME/CFS, we encourage the CDC to work with the IACFS/ME to adapt the high quality content of the Primer into a new Toolkit that meets the CDC's stated goal of providing an easy to use guide for physicians. We request and recommend that this new short version be made available through the CDC website no later than January 2, 2013.

Rationale for the recommendations

As stated above, the CDC CFS website and key resources like the Toolkit provide an authoritative source of ME/CFS information for many doctors, secondary medical educators,

health clinics, insurance companies public health departments and newly diagnosed patients and their families. Over 17,000 copies of the Toolkit have been distributed to date and the CDC continues to make the Toolkit “available primarily as an educational tool for primary care physicians and public health professionals”. (19) The CDC has stated that “It’s surprising how many public health officials around the country are unaware of CFS” and that they are “trying to change that by providing information through the Toolkit.” (19)

For the Toolkit and the rest of the CDC CFS site to fill this role as the authoritative source of ME/CFS information and for it to effectively educate primary care physicians, it must provide the most up-to-date, accurate information on the nature of ME/CFS and its diagnosis and treatment.

Unfortunately, the Toolkit utterly fails to accurately educate providers about ME/CFS. It fails to provide accurate and up-to-date information and worse, the information that it does provide creates significant confusion about the nature of ME/CFS, which directly harms patients.

This confusion and resultant harm has been caused by three fundamental issues:

- The use of Fukuda (6), an eighteen-year old overly broad research definition, as the foundation of clinical guidance documents
- The failure to incorporate advancements in scientific understanding and the current practices of ME/CFS experts
- The inappropriate inclusion of recommendations for “CBT” and “GET”

On each of these dimensions, the IACFS/ME Primer is far superior to the Toolkit. The IACFS/ME Primer is based on the 2003 Canadian Consensus Criteria (CCC), a clinical definition considered to be much more descriptive of the key symptoms of ME/CFS than the Fukuda criteria. (21) Basing the Primer on the CCC translates directly into clinical guidance that is much more targeted to ME/CFS patients. Additionally, the IACFS/ME Primer incorporates much of the knowledge and practical experience of ME/CFS expert clinicians and researchers that has evolved in the eighteen years since Fukuda was published and it provides a foundation for further refinement. Finally, the IACFS/ME Primer provides appropriate warnings to address the potential for the misuse of CBT and GET, warnings that are missing from the CDC CFS Toolkit.

1. Misapplication of an outdated research case definition for clinical use

The Toolkit is directly based on the 1994 Fukuda definition, a research definition intended to provide a conceptual framework for studying chronic fatigue syndrome and other fatiguing illnesses – not to provide a clinical diagnostic tool. As a result of this focus on fatigue and fatiguing illnesses, the only symptom that is mandatory for a diagnosis of CFS is fatigue. Beyond that, the patient must experience any four of eight symptoms concurrently for six months. All patients whose fatigue is due to an active medical condition are excluded but patients with depression, anxiety or somatoform disorders are included.

More damning, PEM, considered to be the hallmark of ME/CFS (8,22,23), is not mandatory for a diagnosis of CFS according to the Fukuda criteria.

In contrast to the Fukuda definition, the 2003 ME/CFS Canadian Case Definition, used in the Primer, and the 2011 ME International Consensus Criteria (22) were developed as explicit clinical tools to guide physicians’ understanding of this disease. Both require PEM, a symptom that has been objectively demonstrated through gene expression studies done by Light (24) and cardiopulmonary exercise tolerance tests by VanNess and Davenport. (25) The exercise tolerance test results have been replicated by Keller, Vermeulen, and Newton. (26)

Exercise physiologist Staci Stevens, who pioneered exercise tolerance testing at the Pacific Fatigue Lab, has said

“The hallmark of chronic fatigue syndrome is exercise intolerance, so studying it and understanding it and the consequences of post-exertional malaise is essential to understanding what's going on in the illness.... [PEM] is a very objective marker, and the way that we employ testing... allows us to objectively measure those symptoms of post-exertional malaise that very few people actually believe exists.”(27)

The predictable and negative consequence of Fukuda's failure to make PEM mandatory is that it defines a heterogeneous group of patients that includes both ME/CFS patients with the characteristic PEM and patients with other causes of fatigue. In comparing the Fukuda criteria to the Canadian Consensus Criteria in 2005, Jason stated, “The Canadian criteria selected cases with less psychiatric comorbidity, more physical functional impairment, and more fatigue/weakness, neuropsychiatric, and neurology symptoms.” (28)

As problematic as Fukuda's use is in research, its use as the foundation of clinical guidance for ME/CFS in the CDC CFS Toolkit is unacceptable for three key reasons.

- First, by not making PEM mandatory while requiring a six-month waiting period, the Fukuda criteria and, as a direct result, the CDC CFS Toolkit significantly impede doctors' ability to correctly diagnose ME/CFS at the very time when appropriate clinical care can make the greatest difference. At least one study, as well as clinical observations and patient experiences, have suggested that erroneously encouraging patients to push themselves or engage in rigorous exercise programs in the beginning may lead to a decline in clinical status (e.g. progressing from being able to walk to being bedridden). (29) The ME-ICC reinforces this view in stating “No other disease criteria require that diagnoses be withheld until after the patient has suffered with the affliction for 6 months... prompt treatment may lessen the severity and impact.” (22)
- Second, because doctors fail to identify and quantify the extent of PEM using techniques such as those developed at the Pacific Fatigue Lab, they give recommendations for exercise, including aerobic exercise, that are harmful for patients with ME/CFS. (29,30,31)
- Third, by erasing the line between ME/CFS and depression, the Fukuda criteria has contributed substantially to the disbelief and stigma that ME/CFS patients' experience. As Jason stated “The selection of diagnostic signs and symptoms has major implications for which individuals are diagnosed with CFS and how seriously the illness is viewed by health care providers, disability insurers and rehabilitation planners, and patients and their families and friends.” (21)

The Toolkit itself further blurs the line between ME/CFS and depression in declaring that “the [Toolkit] approach may also be considered for people with ‘CFS-like illness’” where “CFS-like illness” is defined as being fatigued for 6 months but not meeting the symptom criteria. It is unreasonable to expect that the same clinical diagnostic and treatment approaches can effectively treat both “CFS-like illness” and ME/CFS.

2. Failure to incorporate advancements in knowledge of ME/CFS experts

The CDC CFS Toolkit has failed to incorporate the advancements in scientific knowledge and practices of expert ME/CFS clinicians that have occurred in the last 18 years while continuing to convey information that is disputed or misleading. These gaps in knowledge

and practices in the CDC CFS Toolkit are demonstrated in a comparison of the CDC CFS Toolkit to the IACFS/ME Primer conducted by Johnson. (32) A summary of the differences is provided in Table 1 and include:

- a. Disease pathology and etiology: The CDC CFS Toolkit provides no information on disease pathology or etiology while the IACFS/ME Primer provides extensive, fully referenced information on ME/CFS pathology and etiology.
- b. Diagnostics: The CDC CFS Toolkit provides very limited information on diagnostics, limiting diagnostic criteria and recommendations for diagnostic tests to that defined in 1994 in Fukuda. The hallmark PEM is optional. Orthostatic intolerance, which Rowe said is seen in 80% of his pediatric patients and likely in a similar percentage of adults, is not mentioned at all. (33) The only lab tests recommended are routine lab tests, which are all likely to be normal in ME/CFS, further reinforcing the belief that ME/CFS is not real. There are no recommendations for further testing to determine treatment options once a diagnosis is made. By contrast, the IACFS/ME Primer makes PEM mandatory and recommends lab tests, such as tilt table tests, that are expected to be abnormal in ME/CFS patients. It also provides symptom-specific tests and information on differential diagnosis.
- c. Treatment: The CDC CFS Toolkit recommends only non-pharmacological treatment focused on behavioral therapies like coping and CBT, graded exercise (GET) and sleep hygiene. Its discussion of pharmacological treatment focuses on warnings against the use of drugs and supplements, including warnings against narcotics for pain and sleep medications that many patients rely on. The only drugs recommended are sleep drugs once sleep hygiene has been shown to not work. It provides very limited information on pacing, a management approach that patients report is critical to avoiding exacerbation of symptoms. It fails to provide warnings about the use of exercise in ME/CFS or about the controversy over the use of CBT. It recommends mental exercises but fails to provide warnings about the risk of PEM from mental activities.

By comparison, the IACFS/ME Primer provides extensive treatment recommendations, including information on the use of a broad range of drugs for a variety of symptoms. The IACFS/ME Primer also includes an extensive section on pacing and PEM and includes crucial warnings about exercise and CBT.

The Primer also includes information on managing related conditions and guidance for areas like severely ill patients, pediatric patients and ME/CFS in pregnancy - guidance that is missing from the Toolkit.

3. The inappropriate inclusion of recommendations for “CBT” and “GET”

The recommendations for CBT and GET in the Toolkit are particularly troubling because of the ambiguity around what is intended. Is CBT intended to help patients avoid push-crash cycles or undo false perceptions of illness? Is GET intended as a curative treatment for ME/CFS that works by reversing deconditioning?

The rationale for the recommendation for CBT is not explicit in the CDC CFS Toolkit. The Toolkit vaguely states that CBT is to help patients “cope with illness and to develop behaviors and strategies that improve symptoms” and adds “in order for CBT to be successful, people in CBT must take personal responsibility for change” implying the failure to get better is the patient’s. But there are no specific references in the Toolkit, leaving it up to the medical provider to determine what is intended. But the CDC CFS CME “Diagnosis and Management of Chronic Fatigue Syndrome” (34) does provide references to support the

recommendation for CBT - the large and broadly publicized PACE trial (20) and other similar studies. A number of these studies use the Oxford criteria (35), which only requires fatigue for 6 months.

The PACE trial manual states “the symptoms and disability of CFS/ME are perpetuated predominantly by unhelpful illness beliefs (fears) and coping behaviours (avoidance). These beliefs and behaviours interact with the participant’s emotional and physiological state and interpersonal situation to form self- perpetuating vicious circles of fatigue and disability.” (20) The trial report states that the aim of CBT is “to change behavioural and cognitive factors assumed to be responsible for perpetuating symptoms and disability.” (20)

Other authors referenced in the CBT section of the CDC’s CFS “Diagnosis and Management” CME support a similar theory; Prins stated, “The art of cognitive behaviour therapy is to broaden the patients’ vision to a future life as a well person... Everyday bodily signs and symptoms were no longer interpreted as indicating CFS.” (36)

Given the above references and also the fact that coping skills is listed separately from CBT in the Toolkit and that, with very limited exceptions, ME/CFS is the only medical disease for which CBT is listed on the CDC website (37), the medical provider must conclude that the Toolkit’s intention is to use CBT to change false illness beliefs, not just help patients cope.

For all the issues that Jason has stated about heterogeneous patient cohorts, the PACE claims for efficacy of CBT should be closely questioned because of the use of the Oxford criteria. But leaving aside questions on efficacy and how improvement was measured in PACE, this style of CBT is based on the underlying theory that ME/CFS is “perpetuated predominantly by unhelpful illness beliefs (fears) and coping behaviours (avoidance)” resulting in deconditioning and further avoidance. The recommendation for this style of CBT is not supported by what is known scientifically about ME/CFS. (2,24,25,26,27,38) The recommendation for CBT reinforces the erroneous conclusion that ME/CFS is “all in the head” and results in additional stress, stigma and harm for ME/CFS patients.

Even worse than CBT, the recommendation for GET is potentially dangerous for patients. GET is described as “starting from a very low, basic level of exercise and/or activity and gradually increasing to a level where people can go about their daily lives.” (1) The Toolkit then directs healthcare providers to Britain’s St. Bartholomew’s GET Guide (39), which describes GET as a technique to treat ME/CFS by addressing the underlying cycle of deconditioning, a rationale advanced in the PACE trial as well. The GET Guide from St. Bartholomew’s states:

“Prolonged inactivity can also affect our sleep, hormonal rhythms, immune system and mood, making it more difficult to cope with day to day activities. The inability to function as before leads to frustration and an eventual lack of motivation for any physical activity. This starts a vicious cycle of avoiding activity and increased fatigue which then results in further deconditioning... Reconditioning the body... can break the vicious cycle of avoiding activity, deconditioning and a boom-bust pattern.”

A similar theory is also discussed by Joyner at the Mayo Clinic who states “physical inactivity and lack of exercise – deconditioning – is one of the most common preventable causes of morbidity and mortality...[and] appears to be a final common pathway for conditions like POTS, fibromyalgia and chronic fatigue syndrome.” (40)

With its focus on deconditioning, St. Bartholomew’s GET Guide emphasizes that patients should “Do what [they] have planned to do, not what [they] feel you can do.” (39) But the

fatigue in ME/CFS is not a result of deconditioning but rather pathological fatigue due to the illness itself. Recommendations for exercise have caused serious harm, especially in the hands of uninformed doctors who recommend aerobic exercise, have told patients to “push through it” and/or do not provide appropriate warnings. As reported by Kindlon (31), numerous patient surveys, especially in Britain where the National Health Service routinely prescribes GET, have reported worsening health from GET. This is admittedly a subjective finding but one that is bolstered by the biological pathologies demonstrated in the work of Light (24), VanNess and Davenport (25) and Stevens (27) discussed above. It is imperative that doctors understand that post-exertional malaise encompasses more than post-exertional fatigue, that serious precautions are required for exercise and even minimal activity can be harmful for the sickest patients.

Given the above, the recommendations for CBT and GET in the Toolkit are unacceptable.

In stark contrast, the IACFS/ME Primer acknowledges the debate around CBT and directly states “CBT may improve coping strategies and/or assist in rehabilitation, but the premise that cognitive therapy (e.g. changing illness beliefs) and graded activity can ‘reverse’ or cure the illness is not supported by post-intervention data.” (2) Instead of CBT and GET, the Primer recommends supportive counseling and the development of coping skills and also provides extensive, fully referenced information on post-exertional malaise, pacing and potential issues with exercise for ME/CFS patients.

Looking Beyond the Toolkit

While this analysis is primarily focused on the Toolkit and the Primer, the same content found in the Toolkit is found across the CDC CFS website and related resources. As a result, all of these areas suffer from the same quality issues and are impacting patients in similar ways.

The CDC has a very valuable opportunity to deliver critically needed high quality information to ME/CFS patients and their doctors by leveraging the content of the Primer in order to improve these other areas of the CDC CFS website, especially in terms of disease pathology, diagnosis and treatment. In addition, there are specific changes that should be made, including:

1. Recognize PEM as a hallmark symptom across the CDC CFS website. If the CDC feels that it is necessary to have guidance to cover patients that do not have the hallmark PEM of ME/CFS, this guidance should be provided separately. One guidance document cannot effectively cover the range of patients that meet the Fukuda criteria and certainly cannot cover both ME/CFS and “CFS-like illness” as stated in the Toolkit.
2. Remove all recommendations for CBT because the treatment intent is ambiguous at best and at worst, will be understood to be the style of CBT used in PACE where the focus is in removing the patient’s false illness beliefs.
3. Remove all recommendations for GET and links to St. Bartholomew’s GET guide as GET is too closely associated with a focus on deconditioning as the underlying cause of the ME/CFS. In its place, add information about pacing, cardiopulmonary exercise testing and how activity can be safely undertaken.
4. Immediately remove the “Recognition and Management of Chronic Fatigue Syndrome: A Resource Guide”. (41)
 - The Resource Guide, found on the same page as the Toolkit, contains much of the same content as the Toolkit and as such, will result in the same provider misunderstanding.

Although it acknowledges PEM and exercise intolerance, it still recommends GET and CBT as the primary treatments without sufficient caveats. Further, it is not clear where some of the information comes from. For example, under prognosis, it states that many acute onset patients are better in two years. However, some reports state that as little as 5% of patients get better. (42) Further, a 25 year follow up study of the Lyndonville outbreak found that, while 80% reported that they no longer had a diagnosis of CFS, they had similar levels of impairment to those reporting that they still had CFS and were also significantly more impaired on 21 of 23 outcomes evaluated than healthy controls. (43) The differences in these perspectives could dramatically affect a physician's understanding of the seriousness of the disease.

- We recognize that a two page format of information about ME/CFS could be useful. If this format is needed, then the CDC should work with the IACFS/ME to develop a new Resource Guide using the content of the Primer.

5. Related to the issues resulting from the heterogeneous cohorts created by the Fukuda criteria are the even more heterogeneous cohorts created by the Empirical Definition. (44) While the Empirical Definition has been largely discredited, the studies that used the Empirical Definition and the resultant findings continue to be published and posted on the CDC website. As a result, they continue to pervert medical providers' understanding of ME/CFS, directly affecting clinical care.

Case in point is the recently released letter to the editor of Psychotherapy and Psychosomatics on coping styles in CFS. In this letter, Reeves reported that CFS patients were more likely to have maladaptive coping styles. (46) Which specific patient cohort does the finding actually apply to? Will providers automatically assume that this applies to ME/CFS patients? Most medical providers will never recognize the issues associated with the case definition and will just remember the headline. This directly affects the medical care that patients receive and the stigma that they experience.

Given that the Empirical studies and resultant findings may not apply specifically to the ME/CFS patients that were in those studies, the CDC needs to remove both the Empirical definition studies and the resultant findings from the CDC CFS website unless it can be proven that the findings do apply to ME/CFS patients.

Conclusion

Patients have suffered for years from inadequate or ill-informed medical care as a result of material like the CDC CFS Toolkit. The IACFS/ME has dramatically raised the bar on clinical guidance for ME/CFS, far surpassing the Toolkit or much of the rest of the content on the CDC CFS website.

With the IACFS/ME Primer, there is finally a real opportunity to substantially improve the care that patients receive while decreasing the likelihood of harm. We strongly recommend that the CDC should remove the Toolkit immediately. Further, they should quickly partner with the IACFS/ME to take the steps needed to make the Primer directly available from the CDC CFS website and leverage the content of Primer to make the CDC CFS website the best that it can be.

One million patients and their doctors are waiting.

Table 1: Comparison of CDC CFS Toolkit and the IACFS/ME Primer

More detailed information is available in Johnson's comparison of the Toolkit and Primer (32)

Section	CDC Toolkit	IACFS/ME Primer
Authors and references	Not provided	International expert ME/CFS clinicians and researchers. Fully references
Case Definition	1994 Fukuda	2003 Canadian Consensus Criteria – widely considered to be more descriptive of ME/CFS
Epidemiology	Not included	Included
Prognosis	Not included	Included
Etiology	Not included	Lists predisposing factors including genomics and triggering factors including genetics
Patho-physiology	Not included	Extensive information about abnormalities of immune system, neuroendocrine dysregulation, brain abnormalities, cognitive impairment, autonomic/cardiovascular disturbances, mitochondrial/energy production abnormalities, and gene abnormalities
Diagnosis	<ul style="list-style-type: none">• Diagnostic tests mostly as specified in Fukuda• Lists 7 co-morbid conditions• 10 exclusionary conditions. Psych focus	<ul style="list-style-type: none">• Basic tests generally the same as Toolkit but expanded array of specific tests recommended based on symptoms - can include pathogen tests• Lists 48 co-morbid including autonomic which is not included in toolkit• Lists 55 exclusionary conditions
Treatment	<ul style="list-style-type: none">• Non-pharmacological treatment focused on coping, CBT, graded exercise and sleep hygiene.• Provides warnings on the use of drugs, and with limited exceptions, does not recommend drugs	<ul style="list-style-type: none">• Pharmacological and non-pharmacological treatment recommendations for sleep, pain, pacing and activity management, fatigue, cognitive problems, depression, anxiety orthostatic intolerance and cardiovascular symptoms, GI and Urinary problems, allergies, chemical sensitivities, treatment for infections and immunological dysfunction.• Provides information on supplements• Provides extensive recommendations on the use of drugs for a variety of ME/CFS symptoms – sleep, pain, cognitive, energy, orthostatic intolerance, cardiovascular. Recommends antivirals, antibacterials where pathogens detected• Potential benefits of drugs are balanced with listing of potential side effects in the Primer.
Other clinical concerns	Not included	Guidance for low functioning patients, pediatric patients, pregnancy, gynecological problems, immunization, surgery and blood donation

References

1. CDC CFS Toolkit - <http://www.cdc.gov/cfs/toolkit/index.html>.
2. "ME/CFS: A Primer for Clinical Practitioners". IACFS/ME. 2012.
<http://www.iacfsme.org/Portals/0/PDF/PrimerFinal3.pdf>
 The IACFS/ME is an international organization of clinicians and researchers involved in the study of ME/CFS and the clinical care of patients with ME/CFS. The IACFS/ME Primer Writing Committee, which developed the IACFS/ME Primer and published it in 2012 was composed of the following researchers and clinicians:
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 - Rosemary A. Underhill, M.B., B.S. Physician Upper Saddle River, NJ, USA,
 - Rosamund Vallings, M.B., B.S. Primary Care Howick, New Zealand
3. Email from Dr. Belay to Mary Dimmock, Denise Lopez-Majano and Billie Moore in response to questions on the CDC's plans regarding the CFSAC recommendation to remove the Toolkit
 1. Also discussed at the June 2012 CFSAC P 54.
<http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac20120514.pdf>
4. June 2012 CFSAC, Discussion on Toolkit – S. Krafchick.
<http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac20120514.pdf> P. 48
5. Examples of CDC websites that link to external information
 1. Epilepsy Clinical Guidelines located at <http://www.cdc.gov/epilepsy/> released by the American Academy of Neurology and International League Against Epilepsy.
 2. Fibromyalgia Diagnostic Criteria located at <http://www.cdc.gov/arthritis/basics/fibromyalgia.htm> - Developed by the American College of Rheumatology and supported by Lilly.
 3. Hemochromatosis located at <http://www.cdc.gov/ncbddd/hemochromatosis/links.html> contains links to the American Liver Foundation, which is a non-profit organization.
 4. CDC CFS Website – links to the St. Bartholomew's GET Guide.
6. Fukuda, K., Straus, S., Hickie, I., Sharpe, M., Dobbins, J., Komaroff, A. and the International Chronic Fatigue Syndrome Study Group. "The Chronic Fatigue Syndrome: A Comprehensive Approach to Its Definition and Study". *Ann Intern Med.* 1994;121:953-959.
7. Estimates of prevalence vary according to the definition used. The CDC website reports 1-4 million numbers but there is a concern that the higher number resulted from use of an overly broad definition that included non-ME/CFS patients. One million is typically used as an estimate of ME/CFS patients.
 1. Jason et al, "The Economic Impact of ME/CFS: Individual and societal costs", *Dynamic Medicine* 2008, 7:6 <http://archive.biomedcentral.com/1476-5918/7/6/>
 2. Reyes, M, Nisenbaum, R, Hoaglin, DC, et al. "Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas". *Arch Intern Med* 2003;163(13):1530–1536
8. Carruthers, Bruce et al. "Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols". *Journal of Chronic Fatigue Syndrome*, Vol. 11(1) 2003. <http://mefmaction.com/images/stories/Medical/ME-CFS-Consensus-Document.pdf>
9. Report, NIH State of the Knowledge Workshop on ME/CFS, April 7-8, 2011.
http://orwh.od.nih.gov/CFS2011/ORWH_SKW_Report.pdf

10. "Chronic Fatigue Syndrome: The Challenges in Primary Care" CDC Medscape CME for CFS. <http://www.medscape.org/viewarticle/759095>
11. CDC CFS website <http://www.cdc.gov/cfs/symptoms/index.html>
12. Jason, L. Corrdai, K. Gress, S. Williams, S. Torres-Harding, S. "Causes of Death Among Patients With Chronic Fatigue Syndrome." *Health Care for Women International*, 27:615–626, 2006 <http://www.ncf-net.org/library/CausesOfDeath.pdf>
13. Jason et al, "The Economic Impact of ME/CFS: Individual and societal costs", *Dynamic Medicine* 2008, 7:6 <http://archive.biomedcentral.com/1476-5918/7/6/>
14. Lu, T., Torres-Harding, S., Jason, L. "The effectiveness of early educational intervention in improving future physicians' attitudes regarding CFS/FM". *Journal of Chronic Fatigue Syndrome*. Vol. 14, #2, pp 25-30 Summer 2007. <http://www.cfids-cab.org/cfs-inform/Managecfs/lu.etal07.txt> - early intervention to improve beliefs
15. Montoya, J. Stanford University talk on Chronic Fatigue Syndrome, March 11, 2011 - <http://www.youtube.com/watch?v=Riybtt6SChU> Minute 6.50 – 7:30
16. Nancy Klimas, M.D., Miami Herald, March 24, 2009. Reported on <http://chronicfatigue.about.com/b/2009/10/15/doctor-caused-ptsd-in-fibromyalgia-chronic-fatigue-syndrome.htm>
17. Bernhard, T. "The Stigma of Chronic Fatigue Syndrome". April 10, 2011 <http://www.psychologytoday.com/blog/turning-straw-gold/201104/the-stigma-chronic-fatigue-syndrome>
18. Bernhard, T. "The Stigma of Chronic Fatigue Syndrome II: Readers Respond". May 6, 2011 <http://www.psychologytoday.com/blog/turning-straw-gold/201105/the-stigma-chronic-fatigue-syndrome-ii-readers-respond>
19. Dr. Belay discussion on the Toolkit, June 2012 CFSAC minutes, p36. <http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac20120613.pdf>
20. White, P., Goldsmith, K., Johnson, A., Potts, L., Walwyn, R., DeCesare, J., Baber, H., Burgess, M., Clark, L., Cox, D., Bavinton, J., Angus, B., Murphy, G., Murphy, M., O'Dowd, H., Wilks, D., McCrone, P., Chalder, T., Sharpe, M. "Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial." *The Lancet* - 5 March 2011 (Vol. 377, Issue 9768, Pages 823-836)
 1. Study Publication - [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60096-2/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60096-2/fulltext)
 2. PACE Trial information - <http://www.pacetrial.org/trialinfo/>
 - CBT Manual - <http://www.pacetrial.org/docs/cbt-therapist-manual.pdf>
 - GET Manual - <http://www.pacetrial.org/docs/get-therapist-manual.pdf>
21. Jason, L, Torres-Harding, S, Jurgens, A, Helgersson, J. "Comparing the Fukuda et al. Criteria and the Canadian Case Definition for Chronic Fatigue Syndrome, *Journal of Chronic Fatigue Syndrome*, Vol 12, 2004 <http://www.cfids-cab.org/cfs-inform/CFS.case.def/jason.etal04.pdf>
22. Carruthers, B., van de Sande, M., De Meirleir, K., Klimas, K., Broderick, G., Mitchell, T., Staines, D., Powles, A., Speight, N., Vallings, R., Bateman, L., Baumgarten-Austrheim, B., Bell, D., Carlo-Stella, N., Chia, J., Darragh, A., Jo, D., Lewis, D., Light, A., Marshall-Gradisbik, S., Mena, I., Mikovits, J., Miwa, K., Murovska, M., Pall, M., Stevens, S. "Myalgic encephalomyelitis: International Consensus Criteria". *Journal of Internal Medicine*. Volume 270, Issue 4, pages 327–338, October 2011. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/full>
23. Additional references for PEM as a cardinal symptom of ME/CFS
 - Jason, L. "An Illness that is Hard to Live With – Or Define". *The Wall Street Journal*. Mar 5, 2011. <http://online.wsj.com/article/SB10001424052748704507404576179031979295592.html>

- Jason, L. "To PEM or Not to PEM? That is the definition for case definition". Research1st. April 27, 2012. <http://www.research1st.com/2012/04/27/pem-case-def/>.
 - Jason reiterated PEM as a cardinal symptom at the CDC August 9, 2012 Patient Outreach teleconference and also said that unrefreshing sleep and cognitive issues are key symptoms. None of these are required by Fukuda.
24. Light AR, White AT, Huguen RW, Light KC. "Moderate exercise increases expression for sensory, adrenergic, and immune genes in chronic fatigue syndrome patients but not in normal subjects." *J Pain*. 2009 Oct;10(10):1099-112.
<http://www.ncbi.nlm.nih.gov/pubmed/19647494>
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2757484/?tool=pubmed>
 25. Studies on post-exertional malaise from the Pacific Fatigue Clinic
 - VanNess JM, Stevens SR, Bateman L, Stiles TL, Snell CR. "Post-exertional malaise in women with chronic fatigue syndrome." *J Womens Health (Larchmt)*. 2010 Feb;19(2):239-44. <http://www.ncbi.nlm.nih.gov/pubmed/20095909>
 - Davenport TE, Stevens SR, Baroni K, Van Ness M, Snell CR. "Diagnostic accuracy of symptoms characterising chronic fatigue syndrome." *Disabil Rehabil*. 2011 Jan 6. <http://www.ncbi.nlm.nih.gov/pubmed/21208154>
 26. Replication of exercise tolerance studies
 - Vermeulen, R.C., et al., Patients with chronic fatigue syndrome performed worse than controls in a controlled repeated exercise study despite a normal oxidative phosphorylation capacity. *J Transl Med*, 2010. 8: p. 93. <http://www.translational-medicine.com/content/8/1/93/>
 - Keller, B. Exercise Testing to Quantify Effects of Fatigue on Functional Capacity in Patients With CFS. in *IACFS/ME Biennial Conference; Translating Evidence Into Practice*. 2011. Ottawa, Ontario, Canada.
 - Jones, D. E. J., Hollingsworth, K. G., Jakovljevic, D. G., Fattakhova, G., Pairman, J., Blamire, A. M., Trenell, M. I. and Newton, J. L. (2012), Loss of capacity to recover from acidosis on repeat exercise in chronic fatigue syndrome: a case-control study. *European Journal of Clinical Investigation*, 42: 186–194. doi: 10.1111/j.1365-2362.2011.02567.x
<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2362.2011.02567.x/abstract>
 27. Interview with Dr. Staci Stevens by Llewellyn King, August 6, 2012
<http://forums.phoenixrising.me/index.php?threads/cdc-to-enter-sole-source-contract-with-omi.18738/#post-288576>
 28. Jason, L., Corradi, K., Torres-Harding, S. Taylor, R., King, C. "Chronic Fatigue Syndrome: The Need for Subtypes". *Journal: Neuropsychology Review*, Vol. 15, No. 1, March 2005, pp. 29-58 DOI: 10.1007/s11065-005-3588-2. <http://www.co-cure.org/Jason-7.htm>.
 29. Pheby, D. Saffron, L. Risk factors for severe ME/CFS. *Biology and Medicine*, 1 (4): 50-74, 2009. http://biomedonline.com/Articles/vol1_4_50-74.pdf
 30. (removed)
 31. 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
<http://www.iacfsme.org/BULLETINFALL2011/Fall2011KindlonHarmsPaperABSTRACT/tabid/501/Default.aspx>
 32. Johnson, C. "The Treatment Showdown: CDC Toolkit vs IACFS/ME Primer." *Phoenix Rising*. July 24, 2012 <http://phoenixrising.me/archives/12803>
 33. Rowe, P. June 2012 CFSAC.
http://www.youtube.com/watch?v=C4a41ZspGfw&list=PL600CB038194B4593&index=2&feature=plpp_video
 34. CDC CME "Diagnosis and Management of Chronic Fatigue Syndrome"
<http://www.cdc.gov/cfs/education/diagnosis/index.html>

35. Sharpe M, Archard L, Banatvala J., Borysiewicz, L., Clare, A., David, A., Edwards, R., Hawton, K., Lambert, H., Lane, R. "A report—chronic fatigue syndrome." J Roy Soc Med 1991; 84: 118-121. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1293107/>
36. Prins, J., Bleijenberg, G., van der Meer, J. "Chronic fatigue syndrome and myalgic encephalomyelitis". The Lancet, Volume 359, Issue 9318, Page 1699, 11 May 2002. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(02\)08577-X/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(02)08577-X/fulltext)
37. Based on searches with Google on the following CDC site, searches on the CDC website show that the term "CBT", with rare exceptions, is used only as a treatment for ME/CFS or for depression, anxiety, or for patients dealing with violence or trauma, quitting smoking or losing weight. It is extremely rare to see the CDC website list CBT for other medical illnesses and the few that exist are for dealing with the depression of anxiety resulting from the illness. http://www.cdc.gov/search.do?q=&btnG.x=0&btnG.y=0&sort=date%3AD%3AL%3Ad1&oe=UTF-8&ie=UTF-8&ud=1&site=default_collection
38. Komaroff, A., Cho, T. "Role of Infection and Neurologic Dysfunction in Chronic Fatigue Syndrome." Semin Neurol 2011; 31(3): 325-337. DOI: 10.1055/s-0031-1287654 <https://www.thieme-connect.de/DOI/DOI?10.1055/s-0031-1287654>
39. St Bartholomew's, "Graded Exercise Guide: A self-help guide for those with chronic fatigue syndrome/ myalgic encephalomyelitis", August 2009 <http://drleigh.org/wp-content/uploads/2008/12/chronic-fatigue-exercise-program-specifics.pdf>
40. Joyner, M. Standing up for exercise: should deconditioning be medicalized? The Journal of Physiology, 590, 3413-3414. August, 2012 <http://jp.physoc.org/content/590/15/3413.full>
41. Recognition and Management of Chronic Fatigue Syndrome: A resource guide" <http://www.cdc.gov/cfs/pdf/cfs-resource-guide.pdf>
42. Hill NF, Tiersky LA, Scavalla VR, Lavietes M, Natelson BH. Natural history of severe chronic fatigue syndrome. Arch Phys Med Rehabil. 1999 Sep;80(9):1090-4. <http://www.ncbi.nlm.nih.gov/pubmed/10489014>
43. Brown, M., Bell, D., Jason, L. Christos, C. "Understanding Long-Term Outcomes of Chronic Fatigue Syndrome". Journal of Clinical Psychology. Volume 68, Issue 9, pages 1028–1035, September 2012. <http://onlinelibrary.wiley.com/doi/10.1002/jclp.21880/abstract>
44. Reeves, W., Wagner, D., Nisenbaum, R., Jones, J., Gurbaxani, B., Solomon, L., Papanicolaou, D., Unger, E., Vernon, S., Heim, C. "Chronic Fatigue Syndrome – A clinically empirical approach to its definition and study". BMC Medicine 2005, 3:19 <http://www.biomedcentral.com/1741-7015/3/19>
45. Jason, L., Najar, N., Porter, N., Reh, C. "Evaluating the Centers for Disease Control's Empirical Chronic Fatigue Syndrome Case Definition". Journal of Disability Policy Studies Oct 2008
46. Natera, U., Maloney, E., Lin, J., Heim, C., Reeves, W. "Coping Styles in Chronic Fatigue Syndrome: Findings from a Population-Based Study". Psychother Psychosom 2012;81:127–129. <http://www.alphagalileo.org/ViewItem.aspx?ItemId=121978&CultureCode=en>

Additional background on GET and CBT as described in PACE

The following is quoted directly from the published study report

1. "We selected participants in accordance with Oxford criteria for chronic fatigue syndrome. These criteria require fatigue to be the main symptom, accompanied by significant disability, in the absence of an exclusionary medical or psychiatric diagnosis."
2. "CBT was done on the basis of the fear avoidance theory of chronic fatigue syndrome. This theory regards chronic fatigue syndrome as being reversible and that cognitive responses (fear of engaging in activity) and behavioural responses (avoidance of activity) are linked and interact with physiological processes to perpetuate fatigue."

3. "GET was done on the basis of deconditioning and exercise intolerance theories of chronic fatigue syndrome. These theories assume that the syndrome is perpetuated by reversible physiological changes of deconditioning and avoidance of activity.

The following is quoted from the PACE Trial manual for CBT

1. ***"What factors perpetuate CFS/ME?"*** Just as there are many factors involved in triggering CFS/ME, there are also many factors that are involved in sustaining it. According to this model, the symptoms and disability of CFS/ME are perpetuated predominantly by unhelpful illness beliefs (fears) and coping behaviours (avoidance). These beliefs and behaviours interact with the participant's emotional and physiological state and interpersonal situation to form self-perpetuating vicious circles of fatigue and disability."
2. ***"Theoretical model for GET:"*** GET assumes that CFS/ME is perpetuated by deconditioning (lack of fitness), reduced physical strength and altered perception of effort consequent upon reduced physical activity... There may be other mechanisms involved in the success of GET apart from reversing deconditioning, including elements of habituation, and positive effects of re-engagement with important activities."
3. ***Aim of CBT:*** Treatment aims to help participants improve their levels of functioning, which in turn reduces fatigue. Treatment also aims to help participants become expert in managing their problems so that by the end of treatment they are able to maintain and build on their progress.... A variety of cognitive and behavioural strategies will be discussed with participants during their CBT sessions to help them to improve functioning as a primary goal and to reduce levels of fatigue.

The following is quoted from the PACE Trial manual for CBT

1. ***Model and Rationale behind GET:*** The rationale behind GET stems from both physical and behavioural understanding of CFS/ME. Physical deconditioning, exercise intolerance and avoidance caused by relative inactivity are reversed by gradually and carefully re-introducing regular physical exercise, aiming to return a patient to normal health and ability.
2. ***"Theoretical model:"*** GET assumes that CFS/ME is perpetuated by deconditioning (lack of fitness), reduced physical strength and altered perception of effort consequent upon reduced physical activity... Activity can then produce symptoms as a result of these negative changes, as the body is attempting a physical activity beyond its current capacity. These changes are thought to be reversible, and thus improving fitness and physical functioning will alter perception of effort, enable the body to gain fitness and strength, leading to a reduction in symptoms and an increase in activity capacity ('use it and gain it'). Participants are encouraged to see symptoms as temporary and reversible, as a result of their current physical weakness, and not as signs of progressive pathology.
3. GET encourages "the participant to extend their physical functioning beyond their current ability"
4. "The aim of this treatment is to reverse the physical inactivity that helps to maintain CFS/ME, and to re-engage the participant in physical activity."
5. "A central concept of GET is to MAINTAIN exercise as much as possible during a CFS/ME setback. This is to reduce the many negative consequences of rest, and to allow the body to habituate to the increase in activity. If activity and exercise is reduced at this time, the boom/bust cycle continues, and the body is not able to desensitise to the increase in activity: which is, of course, an essential component of a graded increase in exercise and activity."