

In September 2016, I attended a meeting at the Centers for Disease Control as #MEAction's representative. Also present were Dr. Ken Friedman, Dr. Mark VanNess, Mary Dimmock, Dr. Lucinda Bateman, Dr. Lily Chu, Wilhelmina Jenkins, Dr. Anthony Komaroff, Dr. Charles Lapp, Dr. Susan Levine, Dr. Dan Peterson, [and many other advocates, clinicians and researchers](#), in order to provide recommendations to change the portion of the CDC's website on myalgic encephalomyelitis geared to the public.

As of late 2016, the website recommended graded exercise therapy and cognitive behavioral therapy as best interventions; did not discuss severe ME or its consequences; and contained language that stakeholders found to be dismissive of the disease as a whole.

As of July 2017, the CDC removed recommendations for graded exercise therapy and cognitive behavioral therapy. Then, in a second round of meetings in which Terri Wilder represented #MEAction, stakeholders gave feedback on the section of the website geared to clinicians.

On July 12, 2018, the CDC launched these new pages geared to practitioners. The CDC has altered and edited pages over time; however, not all recommendations made by stakeholders were taken on board. As a result, some sections of the site continue to misinform medical providers and potentially put patients at risk.

*\*Note: this is an analysis of the CDC's content on ME, not solely the July update to the clinicians' section*

*\* The shaded boxes display text from the CDC webpage.*

**8/1/2018: If you would like to download these recommendations as a pdf, click here: [CDC REVISES ITS INFORMATION ON ME](#)**

The Good:

The CDC's website outlines that exercise can be harmful:

Any activity or exercise plan for people with ME/CFS needs to be carefully designed based on individual presentation with input from each patient. If possible, evaluation by a rehabilitation specialist may be beneficial. For some patients, even daily chores and activities such as cleaning, preparing a meal, or taking a shower can be difficult and may need to be broken down into shorter, less strenuous pieces. While vigorous aerobic exercise can be beneficial for many chronic illnesses, **patients with ME/CFS do not tolerate such exercise routines**. Standard exercise recommendations for healthy people can be harmful for patients with ME/CFS.

There is emphasis on pacing:

ME/CFS affects patients in different ways, and treatment plans should be tailored to address symptoms that are most disruptive or disabling for each patient. It is best to proceed slowly. Expecting patients to return to usual activities should not be the initial management goal because the physical and mental exertion can aggravate symptoms and debilitate patients. An important strategy for patients to learn is how to manage their activities to avoid triggering post-exertional malaise (PEM). This is often referred to as **activity management** (also sometimes called pacing), and requires that patients learn to "listen to their bodies" to be aware of their individual exertional limits, aiming to remain as active as possible without exceeding them. Clinical experts have observed that this process requires "trial and error."

The CDC re-affirms the assertion of the National Academy of Medicine Report (2015) stating that ME isn't psychiatric and there is nothing to the 'secondary gain' narrative:

ME/CFS is a **biological illness**, not a psychological disorder. Patients with ME/CFS are neither malingering nor seeking secondary gain. **These patients have multiple pathophysiological changes that affect multiple systems.**

For the first time, the [CDC includes representations](#) of mild, moderate, and severe myalgic encephalomyelitis, and recognizes the heterogeneity of disease presentation. The site now outlines variability for the individual:

The severity and frequency of the symptoms can vary among patients and can vary for an individual patient. Symptoms can fluctuate during the day, from day to day, and throughout the illness. Some patients may not be obviously ill-appearing during clinical evaluations. However, if patients are severely affected or are having an exacerbation of their symptoms, even visiting a clinic for care might not be feasible at times. Thus, healthcare providers may not see patients when their symptoms are most severe.

And within the ME population:

The spectrum of ME/CFS can range from mild to severe. For example, patients mildly impaired by ME/CFS may be able—with careful planning and activity management—to keep a job or continue their education, participate in social and family activities, and attend to daily life. Those patients who are moderately impaired might, for example, have trouble maintaining a regular work schedule or standing and sitting for prolonged periods. Patients who are severely or very severely affected by ME/CFS include those who are completely wheelchair-dependent and house- or bed-bound for months or even years. Some primarily house-bound patients have increased symptoms after trips for healthcare or after performing daily tasks that healthy people take for granted, such as bathing, showering, and cooking meals. Those who are bed-bound might need assistance performing even these basic tasks.

The etiology and pathophysiology section describes common biomedical aberrations in people with ME:

The [Etiology and pathophysiology page](#) reiterates that ME is an embodied illness rather than a psychological disorder.

It also lists several common findings in people with ME, including [NK cell dysfunction](#) and T cell dysfunction; elevated [inflammatory cytokines](#) and increased autoimmunity; cellular [metabolism abnormalities](#); neuroendocrine issues; and issues [maintaining heart rate and blood pressure](#). These specific abnormalities both underline that ME is an embodied illness and reiterate the need for diagnostic testing.

The CDC acknowledges the lack of education and negative attitudes among healthcare providers:

Some of the reasons that people with ME/CFS have not been diagnosed include limited access to healthcare and a lack of education about ME/CFS among healthcare providers. Most medical schools in the United States do not have ME/CFS as part of their physician training. The illness is often misunderstood and might not be taken seriously by some healthcare providers. More education for doctors and nurses is urgently needed so they are prepared to provide timely diagnosis and appropriate care for patients.

The Bad:

Advice on exercise may still lead to harm.

For some patients with ME/CFS, even daily chores and activities such as cleaning, preparing a meal, or taking a shower can be difficult and may need to be broken down into shorter, less strenuous pieces. Rehabilitation specialists or exercise physiologists who know ME/CFS may help patients with adjusting to life with ME/CFS. Patients who have learned to listen to their bodies might benefit from carefully increasing exercise to improve fitness and avoid deconditioning. However, exercise is not a cure for ME/CFS.

While we welcome the inarguable statement that exercise cannot cure ME, parts of this paragraph are troubling.

Moderate and severe patients are not capable of even the levels of activity necessary to avoid deconditioning; and for severe patients, it is not possible to shower or prepare a meal even when those activities are broken down into smaller parts.

In addition, the suggestion that rehabilitation specialists and exercise physiologists who know about ME are generally helpful is misleading. Few specialists understand ME well enough to understand that the price a patient pays to overcome deconditioning may be a permanent worsening of baseline symptoms. And a [rehabilitation specialist](#) -- a professional who helps patients resume their normal lives after an accident, injury, or trauma -- does not seem appropriate in a disease where so few will ever ‘resume their normal lives’.

ME/CFS affects patients in different ways, and treatment plans should be tailored to address symptoms that are most disruptive or disabling for each patient. It is best to proceed slowly. Expecting patients to return to usual activities should not be the initial management goal because the physical and mental exertion can aggravate symptoms and debilitate patients. An important strategy for patients to learn is how to manage their activities to avoid triggering post-exertional malaise (PEM). This is often referred to as **activity management** (also sometimes called pacing), and requires that patients learn to “listen to their bodies” to be aware of their individual exertional limits, aiming to remain as active as possible without exceeding them. Clinical experts have observed that this process requires “trial and error.”

Likewise, returning to usual activities is neither an initial **nor** a final management goal. Returning to usual activities is not typically possible for people with ME.

There is a risk that patients and clinicians may draw incorrect conclusions from this statement. Just as importantly, insurance companies may judge that it should be possible for patients to resume their normal lives -- given time, and the proper rehabilitative therapies.

There is a conflict here between overt statements made previously by the CDC that few adults will ever regain full function, and a seemingly intractable emphasis on rehabilitation and recovery.

Moreover, **in the pediatric section**, it appears some parts have been edited more closely than others, leaving statements side-by-side that contradict one another. There is an emphasis on “push-crash” cycles that is worrying:

Patients with ME/CFS need to avoid ‘push-and-crash’ cycles through carefully managing activity. “Push-and-crash” cycles are when someone with ME/CFS is having a good day and tries to push to do more than they would normally attempt (do too much, crash, rest, start to feel a little better, do too much once again). This can then lead to a “crash” (worsening of ME/CFS symptoms).

Most patients will attempt to fulfill their activities of daily living, if they are able. The focus on finding a balance between inactivity and excessive activity is misplaced. Maintaining our baseline is a matter of staying within our aerobic limits; yet even that isn't always enough to prevent a crash.

Moreover, an emphasis on push-crash cycles supports the narrative that the patient is at fault for their debility by choosing a behavior that is maladaptive or incorrect. This is especially frustrating in light of the fact that in addition to activity, crashes can be caused by sensory stimulation, like bright light or loud noises; infection; hormonal changes; or a reaction to a new medication, food, or chemicals... factors that are generally not within the patient's control.

The pediatric section appears as though important new information has been added, but contradictory elements have been left intact:

Any activity or exercise plan for children with ME/CFS needs to be carefully designed with input from each patient. While vigorous aerobic exercise is beneficial for many chronic illnesses, patients with ME/CFS do not tolerate such exercise routines. Standard exercise recommendations for healthy people can be harmful for patients with ME/CFS. However, it is important that patients with ME/CFS undertake activities that they can tolerate.

For patients with ME/CFS, it is important to find a balance between inactivity and excessive activity, which can make symptoms worse. This means a new way of thinking about daily activities. For example, daily chores and school activities may need to be broken down into smaller steps.

A symptom diary can be very helpful for managing ME/CFS. Keeping daily track of how patients feel and what patients do may help to find ways to make activities easier.

Rehabilitation specialists or exercise physiologists who know ME/CFS may help patients with adjusting to life with ME/CFS. Patients who have learned to listen to their bodies might benefit from carefully increasing exercise to improve fitness and avoid deconditioning. However, exercise is not a cure for ME/CFS.

Parents/guardians and doctors of children with ME/CFS can work with teachers and school administrators to adjust the school load for children with ME/CFS. While it is true that exercise can benefit children with certain chronic illnesses, children with ME/CFS should avoid activity that makes their symptoms worse.

A child with ME does not need an exercise plan, though they might benefit from help with pacing or activity management. The above contradicts other sections of the website, which explicitly advise against exercise.

Prognosis is painted in a positive light.

Since ME/CFS can be unpredictable and can change over time, **evaluation of each patient's condition at scheduled intervals is warranted**. As with many chronic illnesses, length of intervals between visits might vary from patient to patient and depends on the severity and degree of symptom improvement and control. The scheduled re-evaluations serve as opportunities to **adjust the treatment strategies as needed based on patient status**. While it may take some time to experience an improvement and not all patients may improve significantly, it is important to communicate to patients that improvement is possible.

And:

The percentage of ME/CFS patients who recover is not well-studied, but there is evidence and experience to indicate that patients benefit when diagnosis and management are timely and appropriate. Some patients return to full function. Some who improve continue to experience symptoms and do not achieve pre-illness

levels of function, and many who improve continue to modify their activities to remain improved or symptom-free. Some do not improve or, in fact, worsen over time. Even though more studies are needed, most experts agree that children, including teenagers, with ME/CFS have a better chance of full or partial recovery than adults

Anyone who has gone undiagnosed for years or even decades understands that an accurate diagnosis and useful management strategies -- such as avoiding overactivity and providing symptomatic relief -- can improve quality of life. But there is no evidence that early intervention affects the likelihood of full recovery. When the CDC has been so cautious regarding what it recommends as treatment, this assertion, which is insupportable with current evidence, stands out. In addition, while it is technically true that “some patients return to function,” the recovery rate is only 5% after five years. This oft-repeated figure likely comes from [a meta-analysis](#) that used the Fukuda and Oxford criteria, which are known to capture [patients who are not as ill on average](#) as those who have been diagnosed with criteria that involve PEM; so these recovery statistics may well be inaccurate for CCC, ICC, and/or IOM-diagnosed patients.

Diagnostic criteria are in a section called ‘Understanding Historical Case Definitions and Criteria.’

The name of this page -- [Understanding Historical Case Definitions and Criteria](#) -- disregards not just that many consider ‘older’ definitions such as CCC or ICC superior, but that many of them are still in day-to-day use in both research and clinical care. Many scientists, clinicians, and advocates strongly prefer the CCC or ICC for their greater level of detail and specificity; and others use multiple criteria in their research studies.

The reliance on the IOM criteria can lead to omissions of neurological, gastrointestinal, immune, and other systems with dysfunction in ME, because the IOM does not require them for diagnosis. Though additional symptoms are mentioned on the ‘historical definitions’ page, the framing makes it appear as though these symptoms are no longer important for diagnosis. This creates a knowledge gap that may prevent physicians from recognizing the disease in clinic.

The general practitioner is expected to develop a treatment plan.

Because ME/CFS is a complicated illness, its management may require input from a variety of medical professionals. Primary care providers can develop effective treatment plans. When expertise is available and accessible, these plans can sometimes be enhanced through collaboration with clinical specialists and a team of other health care professionals such as rehabilitation specialists, mental health professionals, and physical therapists.

There is no mention here of rheumatology, immunology, neurology or other specialities that might be important to someone experiencing the symptoms of ME. The implication is that referral ought to be rare, and that physical therapy or mental health services are the extent of extra expertise a GP will need to address patient concerns. This is especially troubling in light of previous CDC recommendations being graded exercise therapy and cognitive behavioral therapy!

As for specialists in ME itself, it is often difficult to find a physician who knows how to perform a thorough medical evaluation specifically for people with ME. Many would have to travel across the country to see an expert in myalgic encephalomyelitis, provided they are physically and financially able. The lack of knowledgeable clinicians is a crisis in ME care, and it would have been useful if the CDC had chosen to show clinicians that if they specialize in ME, they will be filling a void of expertise in the medical community.

Milder cases are presented as the norm.

In the ‘Patient Voices’ section, three people with ME discuss their experiences with the disease, presumably to represent the full spectrum of illness experience. However, these are a physician who works six hours a day

with a two hour break in between; a woman who finished her graduate degree, works part-time, and started a family; and a patient who spends a great deal of her time bedbound. These narratives omit the severe patient -- or 'very severe' patient -- who may be unable to communicate, unable to tolerate sensory input, and may be fed through a tube. Communication with the caregiver of such a patient would have been welcome.

Severe patients are represented in some places in the site, but conspicuously missing in others, such as the section mentioned previously, in which high-energy tasks such as cooking a meal are still painted as possible if broken down into smaller chunks.

The etiology and pathophysiology section mentions emotional trauma as a potential trigger for ME:

The [Etiology and pathophysiology](#) page unfortunately lists 'emotional or physical trauma' as a potential trigger for ME.

There is no credible evidence that emotional trauma is any more associated with ME than it is in any other critical illness.

Sleep hygiene recommendations are often inappropriate in ME.

Sleep hygiene includes storing electronic devices away from the bedroom, being active during the day, and going to sleep at the same time every night. Moderate and severe patients -- those who are housebound or bedbound -- spend the majority of their time in their bedrooms and represent one of four patients with ME. They cannot store the items they need far away, be active, or sleep at regular intervals. Sleep hygiene advice may be very useful in other chronic diseases, but can be inappropriate in ME.

Recommended Changes to the CDC Webpages on ME/CFS:

We will be sending these recommendations to the CDC. Did we miss anything? What changes or additions would you like to see made? Write in the comments below.

A special thanks to the *fleet* of patients who have helped by engaging with the CDC for the past few years -- or the past few decades. I could not have written this without their feedback and assistance, and we would not be here without them.

| Recommendation  | Rationale  |
|---|--|
| <p>The entire spectrum of the disease from “mild” to “very severe” needs to be represented in every section of the website. <b>Clinicians should also be aware that some patients are progressive, while others may get better and worse over time.</b></p>   | <p>Very severe patients’ stories are still missing. Their inclusion is vital to provide a complete and comprehensive picture of the disease.</p> <p>It is important for healthcare providers to understand the needs of those who are very severely ill as this population can face enormous barriers accessing life-saving support.</p>   |
| <p>Include the story of a patient or carer of a long-term, completely bed-bound patient in the “Voice of the Patient” section.</p>  |  |
| <p>Under “The spectrum of ME/CFS can range from mild to severe” add: “those on the “very severe” end of the spectrum may require parenteral nutrition.</p>  |  |
| <p>In the <a href="#">Clinical Care of Patients with ME/CFS</a> section, delete the “Primary care providers can develop effective treatment plans” and replace with “Primary care providers can coordinate effective treatment plans in collaboration with rheumatologists, <b>immunologists</b>, neurologists, cardiologists, endocrinologists, <b>infectious disease specialists</b> and, where possible, an ME specialist. <b>People with ME may find it challenging to attend multiple appointments, and may benefit from home visits.</b>”</p> | <p>Many ME patients are diagnosed with immune deficiencies, chronic infections, endocrinological issues and/or neurological abnormalities. The idea that primary care providers can manage ME patients on their own, especially those patients more severely affected, is unrealistic. We recognize that patients cannot always find or afford an ME specialist.</p> <p><b>Moreover, specialist assistance is required in order to receive SSI/SSD benefits, and patients must continue to see their specialist every six weeks. Coordination of care by a general practitioner is not viable when the patient requires specialist visits to maintain their legal obligations to receive disability.</b></p> |
| <p>Remove “Rehabilitation specialists or exercise physiologists who know ME/CFS may help patients with adjusting to life with ME/CFS. Patients who have learned to listen to their bodies might benefit from carefully increasing exercise to improve fitness and avoid deconditioning.”</p>  | <p>Very few exercise physiologists or rehabilitation therapists understand the unique exercise physiology of ME. Referring patients to non-experts runs a very high risk of causing harm, especially if the clinicians do not understand the aerobic impairment that is part of the disease. <b>Moreover, advising patients to carefully increase exercise to avoid deconditioning implies that ME progression is linear and predictable, and lacks the confounding context of delayed PEM.</b></p>  |

In the “treatment” section “Orthostatic Intolerance” mention the importance of confirming OI using a tilt table test or recording *in clinic* of blood pressure and heart rate in both a supine and standing position after at least 10 minutes of being supine **and at 10 minute intervals. The NASA lean test is an especially useful test for impaired patients.** Simply taking a **standard** blood pressure and pulse **reading** of a seated patient **(as is standard) may not reveal dysfunction.**

Moreover, it is important to mention the classes of medications available that can improve these symptoms as many general practitioners are unfamiliar with how to treat OI pharmacologically. Replace “Prescription medications can be considered” with “Prescription medications, such as beta blockers or medications for low blood pressure or low blood volume can be considered.”

**Include common testing and monitoring devices as clinical recommendations.**

- Both patients and clinicians have found the use of heart rate monitors to be helpful in avoiding PEM and maintaining well-being.
- Some studies ([Berkovitz et al., 2009](#), e.g.) have found that patients with ME have significant Vitamin D deficiency, and there is abundant research that Vitamin D stores are low in other chronic disease ([Wang et al., 2017](#)). Testing Vitamin D is cheap and Vitamin D deficiency is easy to address.
- Some studies show that B vitamin supplementation has shows positive outcomes in ME patients ([Regland et al., 2015](#)). Testing for B12 deficiency is another cheap medical test that has potentially significant therapeutic utility.
- In-depth immunological and endocrinological testing may reveal treatable abnormalities in ME patients.

**Include suggestions for accommodations for severe patients.**

- Recumbent wheelchairs
- Portable cook surfaces and bedpans
- Shower chairs
- Home visits

General practitioners may be unaware of specific diagnostics, drugs or interventions that are not already a part of their knowledge-base. By giving them specific and clear recommendations, the CDC will ensure clinicians are more likely to know how to proceed to best serve their patients.



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| <p>Remove “push-crash cycles” and downgrade emphasis on ‘staying active’ and ‘avoiding deconditioning’.</p>  | <p>‘Push-crash cycles’ imply the patient is responsible for their own debility, when in fact crashes are often caused by stimuli entirely outside of the patient’s control. <b>While avoiding deconditioning is desirable where possible, the emphasis on deconditioning devalues patients’ reality: that they are inactive due to necessity, not due to the lack of skilled physical therapy. Patients must purchase groceries, brush their teeth, or engage in necessary mental stimulation such as conversation to ensure their needs are met. For many patients, these ordinary, everyday activities are enough to precipitate an episode of post-exertional malaise. This is not ‘pushing’ but engaging in the minimal activity necessary to maintain their health and hygiene to whatever extent they can.</b></p> |
| <p>Remove emphasis on recovery. The majority of patients do not return to good health.</p>   | <p>While presenting a more positive outlook may decrease physician discomfort in dealing with a chronic and debilitating disease like ME, it is disingenuous to imply that patients will return to good health when so few do. Moreover, this can delay patients from getting the social support they need to cope with a lifelong illness.</p>  |
| <p>Add to “other common symptoms” the missing symptoms described in the CCC and ICC, including muscle weakness, muscle fatigability and fasciculations; aphasia; vision problems; genitourinary issues; heart palpitations; and/or dyspnea -- as these are often part of a patient’s symptom complex.</p> <p>Add the CCC and the ICC to the “Diagnosis” page and do not refer to them as ‘historical’.</p> | <p>The National Academy of Medicine’s 2015 criteria omits important neurological and autonomic symptoms from its diagnostic algorithm that may help physicians recognize the disease in clinic and recognize and address common symptoms.</p>  |
| <p>Under “Factors complicating the Diagnosis of ME/CFS” in addition to “For some patients with ME/CFS, it may not be obvious to healthcare providers that they are ill” a factor that must be added is “Severe patients may be too ill to ever come to the clinic. Others may worsen over time, and be unable to visit the clinic anymore.”</p>  | <p>In their clinics, doctors are more likely to see mild- and moderate-presenting than severe patients. This means that doctors’ clinical experience may create a misleading picture of the full range of disease severity.</p>  |
| <p><b>Post-exertional malaise, despite its name, can be induced through sensory and cognitive effort as well as through physical exertion. This should be emphasized on any section containing information about post-exertional malaise.</b></p>  |  |