

Recommended Changes to the CDC Webpages on ME

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Based on an [analysis](#) by #MEAAction Director of Scientific & Medical Outreach, Jaime Seltzer, and 66 comments from the ME community.

Recommendation	Rationale
<p>The entire spectrum of the disease from “mild” to “very severe” needs to be represented in every section of the website. Clinicians should also be aware that some patients are progressive, while others may get better and worse over time.</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 Clinical Care of Patients with ME/CFS 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, immunologists, neurologists, cardiologists, endocrinologists, infectious disease specialists and, where possible, an ME specialist. People with ME may find it challenging to attend multiple appointments, and may benefit from home visits.”</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>Moreover, specialist assistance is required in order to receive SSI/SSD benefits, and patients must continue to see those specialists every six weeks. Recommending coordination by a general practitioner is not viable when the patient is disabled.</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. 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.</p>

<p>In the “treatment” section “Orthostatic Intolerance” mention the importance of confirming OI using a tilt table test or recording <i>in clinic</i> 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.</p> <p>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.”</p>	<p>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.</p>
<p>Include common testing and monitoring devices as clinical recommendations.</p> <ul style="list-style-type: none"> ● 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 	

<p>Vitamin D is cheap and Vitamin D deficiency is easy to address.</p> <ul style="list-style-type: none"> ● 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. 	
<p>Include suggestions for accommodations for severe patients.</p> <ul style="list-style-type: none"> ● Recumbent wheelchairs ● Portable cook surfaces and bedpans ● Shower chairs ● Home visits 	
<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. 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</p>

	<p>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.</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>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.</p>	