



#MEAction recommended changes to <https://askjan.org/disabilities/Chronic-Fatigue-Syndrome.cfm>

CURRENT CONTENT	RECOMMENDED CHANGE	CHANGE EXPLANATION
<p><b>CHRONIC FATIGUE SYNDROME</b></p>	<p>Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)</p>	<p>The name of the page and all references and links to Chronic Fatigue Syndrome, including page navigation and lists of disabilities, should be replaced with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS).</p> <p>The terminology of CFS is outdated. <a href="#">NIH</a>, <a href="#">SSA</a>, <a href="#">CDC</a> use the term ME/CFS.</p> <p>See also the ME/CFS Clinician Coalition <a href="#">website</a>.</p>
<p>In order to receive a diagnosis of CFS, a patient must satisfy two criteria. First, an individual must have severe chronic fatigue of six months or longer duration with other known medical conditions excluded by clinical diagnosis. Second, an individual must concurrently have four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern, or severity; erratic sleep; and malaise lasting more than 24 hours.</p>	<p>ME/CFS is a complex illness and symptoms of ME/CFS may seem similar to many other illnesses. ME/CFS requires <b>three</b> symptoms:</p> <p><b>Not being able to participate in routine activities that were possible before becoming ill</b>, such as work, school, social life, and/or personal life, that:</p> <ul style="list-style-type: none"> <li>• Lasts for more than 6 months</li> <li>• Is accompanied by fatigue that is:</li> <li>• Often serious</li> <li>• Just started (not lifelong)</li> <li>• Not the result of ongoing activities</li> <li>• Not from more than usual effort</li> <li>• Not made better by rest</li> </ul>	<p>The current page content summarizes the 1994 Fukuda criteria for CFS, which lists post-exertional malaise (PEM) as an <b>optional</b> symptom.</p> <p>However, the 2015 National Academy of Medicine <a href="#">report</a> developed a <a href="#">new clinical definition for ME/CFS</a> that lists PEM as a required, hallmark symptom of ME/CFS (among other differences). The CDC has adopted and updated its website content to reflect this change.</p> <p>Fukuda and other clinical disease definitions that do not require PEM should not be used to identify ME/CFS patients because they can capture a very different cohort of patients that do not experience PEM.</p>



	<p><b>Post-exertional malaise (PEM).</b> Worsening of symptoms after physical, mental, or emotional effort that would not have caused a problem before the illness. Symptom onset can be immediate or delayed for hours or days. This is sometimes referred to as “crashing” by people with ME/CFS.</p> <p><b>Unrefreshing sleep.</b> People with ME/CFS may not feel better even after a full night of sleep (e.g., feeling just as tired upon waking up as before going to bed).</p> <p>In addition, <b>at least one</b> of the following symptoms is also required:  <b>Impaired memory or ability to concentrate.</b> People with ME/CFS may have trouble remembering, learning new things, concentrating, or making decisions.</p> <p><b>Orthostatic intolerance</b> (symptoms that occur while standing or sitting upright). People with ME/CFS may feel lightheaded or dizzy when standing upright and may even faint.</p>	<p>PEM is a unique symptom that is not the same as experiences of fatigue after overexertion in healthy individuals. It is not the same as being more tired than normal after activity and is the exacerbation of multiple symptom domains, not just fatigue.</p> <p>Critically, graded exercise is not an appropriate treatment for people with ME/CFS who have the hallmark symptom of PEM. Accurately distinguishing ME/CFS from older CFS definitions has important implications for seeking safe, appropriate treatment and not causing harm to patients.</p> <p>The recommended changes follow the CDC’s description of ME/CFS found here:  <a href="https://www.cdc.gov/me-cfs/pdfs/toolkit/What-is-MECFS_508.pdf">https://www.cdc.gov/me-cfs/pdfs/toolkit/What-is-MECFS_508.pdf</a>  <a href="https://www.cdc.gov/me-cfs/pdfs/toolkit/What-are-MECFS-Symptoms_508.pdf">https://www.cdc.gov/me-cfs/pdfs/toolkit/What-are-MECFS-Symptoms_508.pdf</a></p> <p>For more information on graded exercise is an outdated standard of care for ME/CFS see this Mayo Proceedings <a href="#">article</a>.</p>
<p>In addition to the primary defining symptoms of CFS, some CFS patients have reported a number of other symptoms. They include gastrointestinal, pain, nausea, photosensitivity, respiratory and skin issues, and weight changes. A majority of CFS patients also report mild to</p>	<p>OTHER COMMON SYMPTOMS:</p> <ul style="list-style-type: none"> <li>• Muscle pain</li> <li>• Pain in the joints without swelling or redness</li> <li>• Headaches of a new type, pattern, or severity</li> <li>• Swollen or tender lymph nodes in the neck or armpit</li> </ul>	<p>Remove reference to anxiety and depression. ME/CFS has been stigmatized in the past and inappropriately treated as psychological/somatic. Secondary anxiety or depression that may result from living with a serious chronic illness should not be confused with primary disease symptoms.</p>



<p>moderate symptoms of anxiety or depression. The treatment of CFS focuses on symptom management.</p>	<ul style="list-style-type: none"><li>• A sore throat that is frequent or recurring</li><li>• Gastrointestinal symptoms</li><li>• Genitourinary symptoms</li><li>• Sensitivity to light, sound, touch, and smell</li><li>• Chills and night sweats</li><li>• Visual disturbances</li><li>• Nausea</li><li>• Allergies or sensitivities to foods, odors, chemicals, or medications</li></ul> <p>Disease onset can be either gradual or sudden, and the course can be unpredictable and varies by individual. Some people may appear healthy and “normal” if they are not experiencing symptoms at the time. However, most patients report that everyday activities such as doctor visits or grocery shopping can worsen their symptoms. ME/CFS can become so severe that some people need total care. About a quarter are bedbound or housebound; many are unable to work or go to school.</p> <p>Currently, there are no medications approved specifically for the treatment of ME/CFS. However, healthcare providers can treat the symptoms and comorbid conditions. Techniques to help patients cope with the disease can also improve their quality of life.</p>	<p><a href="https://www.cdc.gov/me-cfs/pdfs/toolkit/What-are-MECFS-Symptoms_508.pdf">https://www.cdc.gov/me-cfs/pdfs/toolkit/What-are-MECFS-Symptoms_508.pdf</a></p>
<p>[insert new content]</p>	<p>Properly <a href="#">managing PEM</a> should be one of the first actions people with ME/CFS take. During PEM, other symptoms may get worse or first appear, including difficulty thinking, problems sleeping, sore throat, headaches, feeling dizzy, or</p>	<p>Taken from CDC information describing the features of PEM: <a href="https://www.cdc.gov/me-cfs/pdfs/toolkit/What-are-MECFS-Symptoms_508.pdf">https://www.cdc.gov/me-cfs/pdfs/toolkit/What-are-MECFS-Symptoms_508.pdf</a></p>



	<p>severe fatigue. PEM can start immediately after the exertion or be delayed for hours or days. It may take days, weeks, or longer to recover from a crash. Sometimes patients may be house-bound or even completely bed-bound during crashes. People with PEM may not always be able to predict what will cause a crash or how long it will last. Practicing pacing strategies to minimize and manage PEM can lead to stabilization or improvements in pain, sleep, fatigue, cognition, and other symptoms. It can also prevent worsening of these symptoms. Pacing activity may improve quality of life considerably and even increase function.</p>	<p>And on how to manage PEM  <a href="https://www.cdc.gov/me-cfs/pdfs/toolkit/Managing-PEM_508.pdf">https://www.cdc.gov/me-cfs/pdfs/toolkit/Managing-PEM_508.pdf</a></p> <p>Understanding and managing PEM is one of the single most important elements for people with ME/CFS to successfully stay in the workforce. If people with ME/CFS aren't able to stabilize their PEM and remain within their activity energy envelope, they need to take steps before there is even more serious deterioration of their health and they become more disabled.</p>
<p>Chronic fatigue syndrome has also been called myalgic encephalomyelitis (ME) and post exertional fatigue syndrome.</p>	<p>[Remove]</p>	<p>Probably no longer necessary to include once the page is retitled ME/CFS. "Post-viral fatigue syndrome" is technically another term sometimes used. A more nuanced explanation of the relationship of the terms CFS, ME, ME/CFS, PEFS, and PVFS is probably beyond the scope of this webpage.</p>
<p><b>Accommodating Employees with Chronic Fatigue Syndrome</b>          People with CFS may develop some of the limitations discussed below, but seldom develop all of them. Also, the degree of limitation will vary among individuals. Be aware that not all people with <del>arthritis</del> will need accommodations to perform their jobs and many others may only need a few accommodations. The following is only a sample of the possibilities available. Numerous other accommodation solutions may</p>	<p><b>Accommodating Employees with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome</b>          People with ME/CFS may develop some of the limitations discussed below, but seldom develop all of them. Also, the degree of limitation will vary among individuals. Be aware that not all people with ME/CFS will need accommodations to perform their jobs and many others may only need a few accommodations. The following is only a sample of the possibilities available. Numerous other accommodation solutions may</p>	<p>Change from CFS to ME/CFS</p> <p>Replace "arthritis" typo with ME/CFS</p>



exist.	exist.	
<p><b>Accommodation ideas:</b></p> <p>By Limitation</p> <ul style="list-style-type: none"> <li>• Decreased Stamina/Fatigue</li> <li>• Memory Loss</li> <li>• Organization/Planning/Prioritizing</li> <li>• Photosensitivity</li> <li>• Sleeping/Staying Awake</li> <li>• Stress Intolerance</li> </ul> <p>By Work-related Function:</p> <ul style="list-style-type: none"> <li>• Light</li> <li>• Stress</li> <li>• Temperature</li> </ul>	<p>By Limitation</p> <ul style="list-style-type: none"> <li>• Decreased Stamina/Fatigue</li> <li>• Dizziness</li> <li>• Memory Loss</li> <li>• Mental Confusion</li> <li>• Noise Sensitivity</li> <li>• Organizing/Planning/Prioritizing</li> <li>• Overall Body Weakness/Strength</li> <li>• Pain</li> <li>• Photosensitivity</li> <li>• Sleeping/Staying Awake</li> <li>• Standing</li> <li>• Stress Intolerance</li> <li>• Suppressed Immune System</li> <li>• Temperature Sensitivity</li> <li>• Use of Mobility Aids</li> </ul> <p><i>OPTIONAL OTHER EXERTION-RELATED</i></p> <ul style="list-style-type: none"> <li>• <i>Carrying</i></li> <li>• <i>Climbing</i></li> <li>• <i>Lifting</i></li> <li>• <i>Pushing/Pulling</i></li> <li>• <i>Walking</i></li> </ul> <p><i>OTHER COGNITIVE DYSFUNCTION-RELATED</i></p> <ul style="list-style-type: none"> <li>• <i>Attention/Concentration</i></li> <li>• <i>Cognition</i></li> <li>• <i>General Cognition</i></li> <li>• <i>Information Processing</i></li> <li>• <i>Reading</i></li> <li>• <i>Visual Processing</i></li> <li>• <i>Writing</i></li> </ul>	<p>CDC and many other sources describe ME/CFS as “a serious, long-term illness that affects many body systems.” The current limitation list does not recognize the scope of symptom domains that can limit worker function.</p> <p>See this Mayo Clinic Proceedings article for more information on the <a href="#">impact and prognosis</a> of ME/CFS, its <a href="#">etiology and pathophysiology</a>, and <a href="#">management</a>.</p> <p>Examples of a missing limitation include Noise Sensitivity. Working in an open office layout could make it even more difficult and distracting for a person with ME/CFS to concentrate and exercise cognitive functions.</p> <p>Orthostatic intolerance is nowhere covered in the current CFS limitations listed. Suggest including Dizziness and Standing.</p> <p>There are many possible exertion-related limitations relevant to not inciting post-exertional malaise (PEM).</p>



	<p>By Work-related Function:</p> <ul style="list-style-type: none"> <li>● Light</li> <li>● Move items/people</li> <li>● Noise</li> <li>● Off-site access</li> <li>● Parking</li> <li>● Policies</li> <li>● Stress</li> <li>● Temperature</li> <li>● Use Cognitive Function</li> <li>● Work Site Access</li> <li>● Work Station Access</li> </ul>	
<b>EXTERNAL LINKS</b>		
[insert new content]	<ul style="list-style-type: none"> <li>- <a href="#">Could you have ME/CFS?</a></li> <li>- <a href="#">What Is ME/CFS?</a></li> <li>- <a href="#">What Are ME/CFS Symptoms?</a></li> <li>- <a href="#">Managing Post-Exertional Malaise (PEM) in ME/CFS</a></li> <li>- <a href="#">Managing Specific Symptoms of ME/CFS: Orthostatic Intolerance, Sleep Problems, Pain, and Memory/Concentration Problems</a></li> <li>- <a href="#">Other Supportive Strategies for Living with ME/CFS</a></li> <li>- <a href="#">Quick ME/CFS Assessment Tool</a></li> </ul>	<p>CDC informational handouts on various aspects of ME/CFS.</p> <p>The CDC ME/CFS homepage is <a href="#">here</a>, but some of these resources are difficult to navigate to and we suggest linking to them directly.</p>
[insert new content]	<p>Disability and ME/CFS  <a href="https://www.cdc.gov/me-cfs/resources/disability.html">https://www.cdc.gov/me-cfs/resources/disability.html</a></p>	<p>CDC information on disability and ME/CFS.</p> <p>Includes ME/CFS-related fact sheet for</p>



		healthcare professionals. It explains the definition of disability and what SSA needs from doctors when evaluating disability in patients with ME/CFS.
[insert new content]	Work: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome <a href="https://workjournal.org/ME-CFS">https://workjournal.org/ME-CFS</a>	2020 Special Section on ME/CFS in <i>Work: A Journal of Prevention, Assessment and Rehabilitation</i>
[insert new content]	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management <a href="https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext">https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext</a>	Mayo Clinic Proceedings 2021. Most up-to-date and comprehensive consensus recommendations from ME/CFS clinicians.
[insert new content]	Stop. Rest. Pace: Pacing and Management Guide for ME/CFS <a href="https://www.meaction.net/stoprestpace/">https://www.meaction.net/stoprestpace/</a>	#MEAction resource explaining PEM, Pacing and activity management.
<a href="#">Chronic Fatigue and Work</a>	[Remove]	Link to UK site broken. Resource likely does not reflect 2021 Updated UK NICE guidelines on ME/CFS and should not be used.
<a href="#">Chronic Fatigue Syndrome - Topic Overview</a>	[Keep]	
[insert new content]	<a href="https://www.webmd.com/chronic-fatigue-syndrome/features/chronic-fatigue-study">https://www.webmd.com/chronic-fatigue-syndrome/features/chronic-fatigue-study</a>	2022 WebMD & CDC study on awareness and stigma across cultural and gender lines.
<a href="#">Dealing with Chronic Fatigue Syndrome</a>	[Remove]	Link to AU site broken. AU has not updated its CFS guidance as the US and UK have. We do not recommend using AU resources.
<a href="#">Occupational Aspects of the Management of</a>	Myalgic encephalomyelitis (or	Remove link. Replace with link to new NICE



<p><a href="#">Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: Evidence-based Guidance for Employees</a></p>	<p>encephalopathy)/chronic fatigue syndrome: diagnosis and management  <a href="https://www.nice.org.uk/guidance/ng206">https://www.nice.org.uk/guidance/ng206</a></p>	<p>guidelines for ME/CFS which were updated in October 2021. Treatment recommendations have changed in the new guidelines. Anything based on old guidelines should no longer be used.</p> <p>A short NICE article explaining some of the changes to guidelines is also here:  <a href="https://www.nice.org.uk/news/article/nice-me-cfs-guideline-outlines-steps-for-better-diagnosis-and-management">https://www.nice.org.uk/news/article/nice-me-cfs-guideline-outlines-steps-for-better-diagnosis-and-management</a></p>
<p><b>Organizations</b></p>		
<p>[insert new content]</p>	<p><b>Workwell Foundation</b>          Workwell Foundation exercise physiologists provide expertise to support a diagnosis, functional assessments, and treatment in the areas of ME/CFS, Fibromyalgia and other fatigue-related illnesses.</p> <p><a href="https://workwellfoundation.org/">https://workwellfoundation.org/</a>  <a href="https://workwellfoundation.org/contact-us/">https://workwellfoundation.org/contact-us/</a></p>	<p>They use cardiopulmonary exercise testing (CPET) to measure an individual's ability to function in a structured work environment. CPET is considered the gold standard for objectively measuring and evaluating functional capacity and fatigue.</p>
<p>[insert new content]</p>	<p>U.S. ME/CFS Clinician Coalition</p> <p>Resources for Medical Providers Caring for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome</p> <p><a href="https://mecfscliniciancoalition.org/">https://mecfscliniciancoalition.org/</a></p>	<p>The U.S. ME/CFS Clinician Coalition was formed in 2018 by a group of American ME/CFS expert clinicians who have collectively spent hundreds of years treating many thousands of ME/CFS patients. Founding members have served on the expert panel that authored the National Academy of Medicine's 2015 report on ME/CFS, have authored primers on clinical management, have contributed to the CDC's medical education initiatives, and have served on the Health and Human Services' CFS Advisory Committee</p>





		<p>before it was sunsetted in 2018. Many founding members have been and continue to be actively involved in ME/CFS research.</p> <p>The goals of the ME/CFS Clinician Coalition are to:</p> <ul style="list-style-type: none"> <li>• Improve clinical care for patients with ME/CFS by promoting and advancing <a href="#">best clinical practices</a> and by providing <a href="#">medical education</a> and evidence-based recommendations</li> <li>• Expand the pool of medical providers with strong expertise in ME/CFS</li> <li>• Provide clinical insights to scientists to accelerate and promote advances in research</li> </ul>
[insert new content]	<p>The Myalgic Encephalomyelitis Action Network (#MEAction)          We are a patient-led organization working for recognition, education, and research so that, one day, all people with ME will have support and access to compassionate and effective care.</p> <p><a href="https://www.meaction.net/info@meaction.net">https://www.meaction.net/info@meaction.net</a>          1217 Wilshire Blvd., Unit 3639          Santa Monica, CA 90403</p>	<p>#MEAction, OMF and Solve M.E. are the three major national ME/CFS nonprofit organizations doing research, education and advocacy on ME/CFS.</p>
[insert new content]	Open Medicine Foundation	<p>#MEAction, OMF and Solve M.E. are the three major national ME/CFS nonprofit organizations</p>



	<p>Open Medicine Foundation (OMF) envisions improved health care for patients suffering from multisystem chronic, complex diseases with collaboration between patients, clinicians, and researchers.</p> <p>29302 Laro Drive, Agoura Hills, CA 91301 USA          Phone: 650-242-8669  <a href="mailto:info@omf.ngo">info@omf.ngo</a>  <a href="https://www.omf.ngo/">https://www.omf.ngo/</a></p>	
<p>[insert new content]</p>	<p>Bateman Horne Center of Excellence</p> <p>Improving lives impacted by myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), post-viral syndromes, and related comorbidities through clinical care, research, and education.</p> <p><a href="https://batemanhornecenter.org/support@batemanhornecenter.org">https://batemanhornecenter.org/support@batemanhornecenter.org</a>          Fax: 801-359-7404</p>	<p>A premiere ME/CFS center of excellence that has partnered with NIH, CDC, National Academy of Medicine.</p>
<ul style="list-style-type: none"> <li>• <a href="#">American Chronic Pain Association</a></li> <li>• <a href="#">American Occupational Therapy Association</a></li> <li>• <a href="#">American Physical Therapy Association</a></li> <li>• <a href="#">Arthritis Foundation</a></li> <li>• <a href="#">Centers for Disease Control and Prevention</a></li> <li>• <a href="#">Genetic and Rare Diseases Information Center (GARD)</a></li> <li>• <a href="#">Institute for Chronic Pain</a></li> <li>• <a href="#">International Association for CFS/ME</a></li> </ul>		<p>Remedy health communities no longer active</p> <p>Environmental Illness link and page have both misspelled "environmental"</p>



<ul style="list-style-type: none"><li>• <a href="#">Mayo Clinic</a></li><li>• <a href="#">MedlinePlus</a></li><li>• <a href="#">National Center for Biotechnology Information</a></li><li>• <a href="#">National Fibromyalgia &amp; Chronic Pain Association</a></li><li>• <a href="#">National Organization for Rare Disorders</a></li><li>• <a href="#">Office on Women's Health</a></li><li>• <del><a href="#">Remedy's Health Communities</a></del></li><li>• <a href="#">The Environmental Illness Resource</a></li><li>• <a href="#">The Solve ME/CFS Initiative</a></li></ul>		
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