



Solve M.E.

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ME/CFS Disease Criteria and Terminology: Research, Inclusion and Community


Myalgic Encephalomyelitis (ME) is the preferred nomenclature for a complex, multi-systemic neuro-immune disease, also known as chronic fatigue syndrome (CFS). ME is a physiological disease that is notoriously complex, misunderstood, and often underdiagnosed. There have been dozens of different names and criteria utilized by doctors, researchers, and patients themselves. Some of these other names and terms include: Systemic Exertion Intolerance Disease (SEID), Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), Post-Viral Fatigue Syndrome (PVFS), Chronic Active Epstein–Barr Virus (CAEBV) Disease, DaCosta's syndrome, effort syndrome, soldier's heart, Neurasthenia, Iceland disease, Akureyri disease, and Royal Free Disease.

Our organization utilizes the term ME/CFS to reflect the common terminology used in government, academic, and scientific discourse. The ME/CFS field currently lacks an agreed upon research or clinical case definition. As with many diseases, the definition used to diagnose ME/CFS for clinical care differs significantly from the definition used to select ME/CFS research cohorts.

A good explanation of this phenomenon can be found on the [Centers for Disease Control and Prevention \(CDC\) website](#):

“It is not uncommon to have more than one case definition that is used to diagnose or study an illness. From a clinical perspective, case definitions are used to make the appropriate diagnosis and guide therapy and management. From a research perspective, case definitions are used to identify the appropriate study population. Multiple case definitions may be required for different applications and can co-exist if there is a good understanding of how they are being used.”

See below (and on the [Open Medicine Foundation website](#)) for an overview of the history and evolution of ME/CFS diagnostic criteria:



CRITERIA FOR ME/CFS DIAGNOSIS

	HOLMES CDC 1988	FUKUDA CDC 1994	CANADIAN CONSENSUS CRITERIA 2003	INTERNATIONAL CONSENSUS CRITERIA 2011	INSTITUTE OF MEDICINE 2015
NAME ACRONYM	CFS	CFS	ME/CFS	ME	SEID
MINIMUM DURATION	6 MONTHS	6 MONTHS	6 MONTHS	NO MINIMUM	6 MONTHS
NEW ONSET (NOT LIFELONG)	REQUIRED	REQUIRED	REQUIRED	REQUIRED	REQUIRED
FUNCTIONAL IMPAIRMENT	50% DECREASED	SUBSTANTIAL	SUBSTANTIAL	50% DECREASED	SUBSTANTIAL

SYMPTOMS					
PERSISTENT FATIGUE	REQUIRED	REQUIRED	REQUIRED		REQUIRED
POST-EXERTIONAL MALAISE	MAY BE REQUIRED	MAY BE REQUIRED	REQUIRED	REQUIRED	REQUIRED
SLEEP DISTURBANCES	MAY BE REQUIRED	MAY BE REQUIRED	REQUIRED	MAY BE REQUIRED	REQUIRED
PAIN	MAY BE REQUIRED	MAY BE REQUIRED	REQUIRED	MAY BE REQUIRED	
MOTOR-SENSORY DISTURBANCES	MAY BE REQUIRED	MAY BE REQUIRED	MAY BE REQUIRED	MAY BE REQUIRED	
RECURRENT FLU-LIKE SYMPTOMS	MAY BE REQUIRED	MAY BE REQUIRED	MAY BE REQUIRED	MAY BE REQUIRED	
COGNITIVE PROBLEMS	MAY BE REQUIRED		MAY BE REQUIRED	MAY BE REQUIRED	MAY BE REQUIRED
SHORT-TERM MEMORY ISSUES	MAY BE REQUIRED		MAY BE REQUIRED	MAY BE REQUIRED	
INFECTION SUSCEPTIBILITY			MAY BE REQUIRED	MAY BE REQUIRED	
SENSITIVITIES FOOD/CHEMICALS			MAY BE REQUIRED	MAY BE REQUIRED	
GASTRO-INTESTINAL TRACT ISSUES			MAY BE REQUIRED	MAY BE REQUIRED	
GENITOURINARY PROBLEMS			MAY BE REQUIRED	MAY BE REQUIRED	
RESPIRATORY PROBLEMS			MAY BE REQUIRED	MAY BE REQUIRED	
CARDIOVASCULAR PROBLEMS			MAY BE REQUIRED	MAY BE REQUIRED	
INTOLERANCE OF TEMPERATURE			MAY BE REQUIRED	MAY BE REQUIRED	
THERMOSTATIC INSTABILITY			MAY BE REQUIRED	MAY BE REQUIRED	
ORTHOSTATIC INTOLERANCE			MAY BE REQUIRED		MAY BE REQUIRED

REQUIRED - SYMPTOM MUST BE PRESENT.
MAY BE REQUIRED - PATIENTS ALSO NEED TO PRESENT A COMBINATION OF THESE SYMPTOMS IN ADDITION TO THE REQUIRED SYMPTOMS.
 SYMPTOMS LEFT BLANK ARE NOT REQUIRED FOR DIAGNOSIS.

Solve M.E.'s Disease Criteria Approach in Research

Solve M.E.'s research programs are designed to improve the ME/CFS research infrastructure and support work that will identify and untangle the complex causes and symptoms; hopefully, leading to the development of treatment(s) and prevention. The research case definition(s) proposed for use in a study is one of the many factors considered in Solve M.E.'s funding decision process. Applications for funding from the [Ramsay Grant Program](#) are subject to a peer review process by a panel that includes members of our [Research Advisory Council](#), experts with relevant scientific expertise, and patient-scientist reviewers. Reviewers are asked to strongly consider the methodology, including the research case definition(s).

Solve M.E. does not direct Principal Investigators (PIs) regarding the use of specific case definitions for applications or research proposals. However, *Solve M.E. requires that the symptom post-exertional malaise (PEM) must be present in determining a case of ME/CFS in funded proposals.*

While measurement, understanding and even the terminology of PEM is often controversial, Solve M.E. strives for an improved scientific understanding of PEM. In the general field of ME/CFS, Solve M.E. educates and encourages our colleagues to include PEM as a requirement in any definition of the disease. As stated in our Researcher guide:

CONSIDER:

PATIENT SELECTION

The ME/CFS field [lacks an agreed upon research or clinical case definition](#). Sample heterogeneity across research studies and disordered patient selection impedes replication and holds back progress in the search for biological markers and effective treatments.

We don't have the space to outline the arguments for one case definition over another in this guide, but this is unequivocal:



A well-designed study will **require the presence of post-exertional malaise (PEM)** in determining a case of ME/CFS.

In order for progress to be made in the study of ME/CFS, Solve M.E. encourages and funds research projects where data is reliable, sensible, and sharable. As part of the NINDS “[Common Data Elements Project](#),” Solve M.E. contributed to improved standardized methods to improve collaboration across different research labs and disciplines. This is especially important for ME/CFS because there are still unidentified subtypes or abnormal disease presentations that may change our future understanding and definitions of ME/CFS. Uncovering potential subtypes of ME/CFS is a key research priority of our organization.

Additionally, specificity of disease definition impacts the future of all research. As stated in the OMF [historical overview](#) of the disease:

From a research perspective, the more specific the definition used, the better. Furthermore, collecting samples for research from patients that have been diagnosed under the same criteria is essential for research. The understanding of different case definitions is crucial to reading the literature of ME/CFS research and determining which studies may be relevant to each other.

If you're a researcher and would like to learn more about ME/CFS disease definitions, please refer to [our research guide](#).

If you are a patient seeking more information on clinical diagnosis and treatments, check out [ME/CFS: A Primer for Clinical Practitioners](#) (July 2014). The “go-to” guide for clinical care, this primer for adult cases was published by the International Association for CFS and ME (IACFSME) and authored by a committee of experts.

In June 2017, a [primer for the diagnosis and management of ME/CFS](#) in pediatric populations was published.

See also the definitions from the [CDC](#) (mentioned above) and [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#) by the National Academy of Medicine (NAM), published February, 2015.

Solve M.E.'s Disease Criteria Approach in the Community

While conflicting disease definitions may complicate research and diagnosis for people with ME/CFS, they do not limit our understanding of the ME/CFS community. At Solve M.E., we use the term ME/CFS Community to refer *inclusively* to people who have been diagnosed as having M.E. or CFS, and to those who are self-identified as members of the ME/CFS community. We also include: caregivers, friends and family members, researchers, scientists, advocates, health care providers, allies and others.

We recognize that there are many reasons why a person may belong or identify to one group or another. We respect the right of community members and individuals to make their own choices in regard to disease definition. Every ME/CFS story is unique.

Some members of the ME/CFS community received a label early in their disease experience, others fought for a formal diagnosis, and still others may hide their diagnosis for personal reasons. Many have self-diagnosed or found this community for other reasons. Many patients experience financial barriers, struggle to access qualified professionals, manage unsupportive caregivers, or face other hardships beyond measure. Healthcare professionals, researchers or even organizations like Solve M.E. should not have the power to serve as gatekeepers for the ME/CFS community; we do not decide who is or is not "ME/CFS."

At Solve M.E., we strive to welcome all community members. In doing so, we promote understanding, education, and awareness of this terrible disease. We believe "We are Stronger Together" and act in collaboration and inclusion with others in order to accomplish our shared goals and *ultimately create a world free of ME/CFS*.