

[Article Index](#)

[Why are U.S. codes problematic](#)

[What are international classification codes?](#)

[Confusion over names and diagnoses](#)

[The new ICD-10-CM code for the U.S.](#)

[Current methods for diagnosing ME/CFS](#)

[Consequences of the U.S. code](#)

[Effects of codes on disability insurances](#)

[What patients can do](#)

[More information](#)

After more than thirty years, U.S. Centers for Disease Control and Prevention (CDC) is adopting an updated classification code for illnesses and diseases. This new code, the International Classification of Diseases-10-Clinical Modification (ICD-10-CM) will supersede the current U.S. code, the ICD-9-CM. Implementation of the new code is scheduled for October 1, 2014.

Why are new codes specific to the U.S. so problematic?

The new ICD-10-CM code will perpetuate the long-standing failure of the current code to properly classify the very real, organic illness, which has been misnamed as Chronic Fatigue Syndrome (CFS). CFS will remain at least partially classified under: "Malaise and fatigue" in the Chapter: "Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified." This vague and uncertain classification is detrimental to CFS patients, since it may encourage physicians and insurance companies to misdiagnose and classify the illness as a psychiatric, and not a physical disorder.

However, the illnesses Postviral fatigue syndrome and benign Myalgic Encephalomyelitis will be classified under "Other disorders of the brain", in the Chapter: "Diseases of the Nervous System". This nervous system and viral classification for ME/CFS is not especially well-known to either physicians or patients. Yet the knowledgeable physician can use this coding to classify ME/CFS, thereby enabling his/her patients to receive proper diagnosis, treatment, and disability benefits.

[Back to top](#)

What are international classification codes and how are they used?

In the United States and in countries around the world, illnesses are classified under an official system termed the *International Classification of Diseases* (ICD). Periodically, the ICD international code, administered by the World Health Organization (WHO) is revised; the current version is the ICD-10. Individual countries, with the permission of the WHO, may modify their codes for their own national purposes. These national revisions are called "Clinical Modifications" (CM). The codes used in the U.S., currently ICD-9-CM (to be updated to ICD-10-CM), is administered by the National Center for Health Statistics (NCHS), which is associated with the Centers for Disease Control (CDC).

Both the U.S. and international codes are used in epidemiology (tracking of illnesses), health management and clinical practice, and billing. The system is used in many types of health records, including mortality and morbidity statistics. The codes are also used by medical insurance and disability insurance companies in their determination of benefits—as well as by Medicaid and Medicare.

[Back to top](#)

Confusion of Names and Diagnoses: CFIDS, CFS, ME and Postviral Fatigue Syndrome (PVFS)

The illness that many patients and knowledgeable physicians refer to as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) actually has two "official" names: Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME); and one official associated name, the Postviral Fatigue Syndrome (PVFS).

To understand the differences in these names and their importance to patients, a little history is in order. The devastating, flu-like illness with neurological and multi-systemic effects was identified as benign Myalgic Encephalomyelitis (bME) and Postviral Fatigue Syndrome (PVFS) by Dr. Melvin Ramsay and other doctors in Europe in the 1950s and 1960s. "Myalgic" means muscle pain and "encephalomyelitis" means inflammation or infection of the brain. Since the 1990s many patients and doctors in England, other European countries, Canada, Australia and New Zealand have used the term ME as the name for the illness. (When ME was first defined in England in the 1950s the word "benign" was attached for a short time; later the illness became simply ME.)

In the United States, in the late 1980s, the same illness came under the scrutiny of the U.S. Centers for Disease Control (CDC). Unfortunately, the CDC constructed a flawed diagnostic criteria to very broadly cover "fatiguing illnesses"—both physical and psychological. The

problem with the illness case definition was that it included patients with the real illness (ME), but it also appeared to include patients with other physical and psychological illnesses, thereby misleading doctors and the public as to the nature and seriousness of ME.

The CDC also came up with a medically unscientific name for the illness: Chronic Fatigue Syndrome. This name trivialized the illness and stereotyped patients as not really sick—they were just depressed or "stressed out", and should by better behavior or thinking, get better.

However, during the 1990s when research demonstrated definite immunological and other physical abnormalities in patients, a number of patient organizations in the U.S. designated the illness as the Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS).

[Back to top](#)

Diagnostic Codings in the new U.S. Code (ICD-10-CM)

As already mentioned, Chronic Fatigue Syndrome, the name most used to identify the illness, will be placed after October 1, 2014 in the vague "orphan" category: Chapter 18, "Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified" (R00-R99). The R53 subsection, in which CFS is placed, is titled "Malaise and Fatigue". CFS is specifically coded as R53.82, "Chronic Fatigue Syndrome, unspecified> Chronic Fatigue Syndrome (NOS)" [Not otherwise specified]. Again, it's not hard to see how this placement undermines a scientific understanding of ME/CFS.

This coding of CFS follows the current ICD-9-CM code (in force for many years) which also places CFS in the vague category: "General Symptoms", in the Chapter: "Symptoms, Signs, and Ill-Defined Conditions". The code for CFS is 780.71. Because most doctors and insurance companies in the U.S. know ME/CFS as Chronic Fatigue Syndrome, the illness has been frequently coded as 780.71.

However, less well known by physicians is the placement both in the current ICD-9-CM and the new, revised code ICD-10-CM of (b)ME and Postviral Fatigue Syndrome (PVFS) under Diseases of the Nervous System. In the ICD-10-CM, (b)ME and PVFS will be coded in Chapter 6 "Diseases of the Nervous System", in the subcategory G93 "Other Disorders of the Brain". G93.3 is the actual code for (b)ME and PVFS.

In the current ICD-9-CM, ME/CFS is classified as a nervous/organ system disease in Chapter 6, "Diseases of the Nervous System and Sense Organs" (320-389), under subheading 320-326 "Inflammatory Diseases of the Central Nervous System". The Tabular Listing gives the specific code as 323.9: "Unspecified cause of encephalitis, myelitis, and encephalomyelitis." The associated Index document lists "Encephalomyelitis (chronic) (granulomatous) (hemorrhagic necrotizing, acute) (myalgic, benign) (see also Encephalomyelitis)" also coded as 323.9.

[Back to top](#)

Diagnosing ME/CFS and assigning a code

Obviously, most patients with ME/CFS will be far better served if they are coded as 323.9 under the current code and under G93.3 when the new code takes effect.

The assignment of a diagnosis and an illness code is usually provided by the patient's own doctor(s). Most U.S. doctors are unfamiliar with the assignment of a nervous system code for ME/CFS—they usually code for CFS under the vague "Signs and Symptoms" category. If a doctor does not understand or fails to pick-up on the viral/nervous system components of the patient's illness, then a patient may be coded as having CFS in the R code, instead of PVFS/ME in the G code.

Many doctors are also unfamiliar with actually how to diagnose ME/PVFS. Obviously, a proper diagnosis of the illness is a requirement before assigning a code. Doctors in the U.S. will usually diagnose the illness as CFS because knowledge of the flawed CDC 1994 CFS definition is more widespread.

Patients and their doctors need to become aware of the proper diagnostic methods for diagnosing ME/CFS. Despite the historical emphasis in the U.S. on the flawed 1994 CFS definition, the CDC has recently begun referring to the illness as ME/CFS.

The best current methods for diagnosing ME/CFS in adults—in line with the nervous system codes are:

- 1) the 2003 ME/CFS Canadian case definition/diagnostic criteria;
- 2) the 2011 ME International Consensus case definition/diagnostic criteria.

In children, the similar ME/CFS diagnostic criteria are:

- 1) the 2006 ME/CFS Pediatric case definition/diagnostic criteria;
- 2) the 2008 ME/CFS Pediatric case definition/diagnostic criteria.

Links to the different case/definition criteria are provided under More Information.

[Back to top](#)

The important practical consequences regarding the classification of patients as having CFS, ME and PVFS

The upcoming revised U.S. code will be used to gather illness statistics and epidemiological data. It will be used to provide for health care utilization, quality review and resource allocation. If most patients continue being classified as having CFS under the R code, there will continue to be a breakdown in the recognition and the provision of treatment for the illness.

Moreover, the publication of the new ICD-10-CM is being closely coordinated with the Centers for Medicare and Medicaid Services (CMS) and the development of IT systems for electronic record keeping. The perpetuation of improper diagnosis will negatively affect how doctors who are reviewing patients' records will respond.

[Back to top](#)

Effects of diagnostic coding on Disability Insurance and Social Security disability programs

The best choice for assigning a name and coding to CFS/CFIDS/ME patients who are applying for disability benefits remains somewhat tricky, at least until a consensus occurs as to the proper name for the illness. The Social Security disability programs have developed their regulations and approval processes for the CFS diagnosis.

On the other hand, the diagnosis of CFS is blatantly used by employer-related and private long-term disability (LTD) policies to severely limit disability benefits. Insurance companies, in the past few years, began to sell policies to employers that limit benefits to CFS and other "subjective" illnesses to two years. The previous generation of policies—many still in force—limited benefits to two years if the individual had a "mental impairment". With CFS coded as a vague illness of malaise and fatigue, and misunderstood by many physicians as being partially psychiatric, the R coding for CFS can serve as an obstacle to obtaining these benefits.

A diagnosis under the G code would be a definite improvement for private or employer-related disability insurance—ME/PVFS would be a much better diagnosis. The physician should emphasize the post-viral causation along with the severity and chronicity of physiological system impairments.

Also, the coding of the illness is important for another reason. If a physician or psychiatrist conceives ME/CFS as a psychiatric illness and uses the R code, it is possible that the patient will be classified by their medical insurance as a psychiatric patient. Medicare only reimburses 50% for a mental health claim, not the usual 80% for a physical illness.

The issue of psychiatric diagnosis for ME/CFS may be somewhat heightened with the upcoming publication of the new Psychiatric Diagnostic Manual 5 (DSM-5) which introduces a new psychiatric diagnosis, Somatic Symptom Disorder (SSD). For more information on this topic, follow the link to our onsite article listed under More Information.

[Back to top](#)

What patients can do

Knowing the diagnostic names, criteria, and coding, including the Canadian ME criteria, the new International Consensus Criteria and the various coding options will allow patients and their physicians to better diagnose, name and code their illness.

The Massachusetts CFIDS/ME&FM Association has always made patient education a priority. Patients and patient associations need to be armed with the important information about the diagnosis and classification of their illnesses.

[Back to top](#)

More information

The 2013 release of the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) is available for public viewing at: <http://www.cdc.gov/nchs/icd/icd10cm.htm>

The 2003 Canadian ME/CFS case definition-diagnostic criteria can be found at: <http://www.cfids-cab.org/MESA/ccpc.html>

The 2011 ME International Consensus Criteria (full text): <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/full>

The 2006 ME/CFS Pediatric Diagnostic Criteria (full text): <http://www.cfids-cab.org/MESA/Jason-1a.pdf>

The 2008 ME/CFS Pediatric Diagnostic Criteria: <http://www.la-press.com/a-case-definition-for-children-with-myalgic-encephalomyelitis-chronic-f-a1147>

[DSM-5 Makes Way for Misdiagnosis of Physical Illness as Mental Disorders](#)—reviews the flaws and risks posed by the new diagnostic criteria, Somatic Symptom Disorder (SSD), included in the fifth edition of the

Diagnostic and Statistical Manual of Mental Disorders.

[Back to top](#)