Diagnosis of ME/CFS

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Why an accurate diagnosis is important

- To be sick and not know what the problem is makes it impossible to know what is happening. It is like being lost without a map.
- By identifying the illness, the patient will know what treatments are available and how to obtain help in coping with ME/CFS.

Symptoms

The most immediate and ongoing experience with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is its symptoms. Unlike many other illnesses,it has different symptoms that may change from day to day, week to week, and month to month. Identification of an ongoing and coherent pattern and clustering of symptoms is an important element in making a diagnosis. As a patient, it is very helpful to see and understand that the number and types and symptoms that you have are, in fact, common to other patients with ME/CFS. It has been shown recently that which symptoms predominate in a patient is influenced by how long since the illness started. It appears that the illness changes it character somewhat after some years.

Here is an extensive list of ME/CFS symptoms which has been drawn up by several international experts on the illness.

Most common ME/CFS symptoms

- Exhaustion, made worse by physical exercise (100%)
- Low-grade fever in early stages (60-95%)
- Recurrent flu-like illness (75%)
- Frequent pharyngitis (sore throats) (50-75%)
- Joint and muscle pain (65%)
- Severe muscle weakness (40-70%)
- Stiffness (50-60%)
- Post-exertional fatigue & flu-like symptoms (50-60%)
- Multiple sensitivities to medicines, foods, and chemicals (40-60%)
- Severe nasal & other allergies (often with worsening of previous mild allergies) (40-60%)
- Frequently recurring, difficult to treat respiratory infections (40-60%)
- Dyspnea (labored breathing or hunger for air) on exertion
- Painful lymph nodes (especially in the neck and under arms) (30-40%)

Neurological Symptoms

- Sleep disorders & unrefreshing sleep (50-90%)
- Headaches (35-85%)
- Visual blurring (50-60%)
- Intolerance of bright lights
- Parasthesias (numbness or tingling feelings) (30-50%)
- Dizziness/ Lightheadedness (30-50%)
- Ringing in the ears
- Impaired cognition (50-85%), which may include:
  - Attentional difficulties
  - Calculation difficulties
  - Memory disturbance
  - Spatial disorientation
  - Saying the wrong word

Other Symptoms

- Worsening of premenstrual symptoms (70% of women)
- Nocturia (excessive urination during the night) (50-60%)
- Tachycardia (abnormal rapid heart action) (40-50%)
- Chest pain (25-40%)
- Cough (30-40%)
- Weight gain (50-70%)
- Nausea, especially in earlier stages (50-60%)
- Diarrhea, intestinal gas or irritable bowel (50%)
- Intolerance of alcohol
- Night sweats (30-50%)
- Dry eyes (30-40%)
- Dry mouth (30-40%)
- Rash (30-40%)
- Frequent canker sores (30-40%)
- Herpes simplex or shingles (20%)
- Symptoms worsened by extremes in temperature

(Statistics compiled from data on CFS patients by: Paul Cheney MD, Anthony Komaroff MD, Charles Lapp MD, Daniel Peterson MD)

What is a syndrome?

In medicine, a "syndrome" is a set of signs and symptoms that occur together in a medical condition. For instance, AIDS is Acquired Immunodeficiency Syndrome, and until infection by the HIV virus was discovered to be the cause, diagnosis of AIDS was made solely by a collection of signs and symptoms. (In medicine, a "sign" is something that can be objectively measured by a physician and a "symptom" is something subjective experienced by a patient, such as severity of pain.)

In the early 1980s, a number of U.S. physicians noticed what seemed to be an emerging syndrome. The Centers for Disease Control and Prevention (CDC) was called in to investigate an outbreak in the Lake Tahoe, Nevada area. The CDC later convened a committee to come up with a research definition of the syndrome using signs and symptoms. This is now known as the **1988 CDC definition** and the illness was named the Chronic Fatigue Syndrome (CFS).

In 1994, the CDC came up with a new research case definition, which loosened the requirements for diagnosis with ME/CFS. This is known as the **1994 CDC definition** Both definitions were intended to be used by researchers, to make sure their research subjects all had the same illness.

Unfortunately, it has been shown that the 1994 requirements were loosened too much compared to the 1988 definition, and people with other illnesses (including depression) were being mistakenly diagnosed as having ME/CFS. This has created major problems for the ME/CFS research results of the last 20 years, since in studies some of the subjects didn't have ME/CFS, but were mixed in with those who did.

Later a Canadian, Dr. Carruthers, led an international team of clinicians to come up with a definition of ME/CFS to be used by physicians who regularly see patients. This was published in 2003 under the auspices of the Canadian Ministry of Health. This **2003 Canadian definition** is what the physician authors of ***ME/CFS: A Primer for Clinical Practitioners*** as well as many other internationally known ME/CFSD clinicians suggest be used for diagnosing ME/CFS.

Diagnostic criteria for ME/CFS

What is Necessary to Receive a Correct and Accurate Diagnosis of An Illness?

Before any illness can be diagnosed, medical science must provide an accurate "case definition" for the illness—a definition that correctly describes the signs, symptoms, illness progression, pathophysiology (deleterious effects of the illness on the body), laboratory abnormalities, and known causal agents. Second, this "case definition" must distinguish the specific illness from other known illnesses—otherwise a specific illness would not be distinguishable from other illnesses, and a diagnosis of it would be impossible.

The preceding discussion is necessary because there has been much confusion and disagreement as to what the illness ME/CFS actually is. Not only is the illness known by various names, but *there are several different case definitions* that describe the illness somewhat differently and provide different diagnostic criteria. Because the illness first became widely identified in the mid-1980s, a number of case definitions and diagnostic criteria were developed as physicians and researchers learned more about the illness.

Because it is a syndrome and thus only diagnosed by a collection of signs and symptoms in a case definition, receiving an accurate diagnosis of ME/CFS can be difficult. A diagnosis must be obtained from a physician who is knowledgeable about the illness, knows how to rule out other illnesses that can cause similar symptoms, and can apply a case definition accurately.

In early 2015, the United States Institute of Medicine proposed another new diagnostic criteria for ME/CFS. As yet this criteria is a proposal and has not been adopted by the Federal Health Agencies, clinical physicians, and researchers. They also proposed a new name, Systemic Exertional Intolerance Disease (SEID). So far this name has not been adopted by anyone else.

As of late 2015, there are two *principal* diagnostic criteria used to diagnosis ME/CFS: the 2003 Canadian Definition and the **1994 Centers for Disease Control definition**. In our view and that of many ME/CFS experts, the Canadian Definition is superior in accurately diagnosing the illness.

Unfortunately, the 2003 Canadian definition of ME/CFS is complex. We will give a summary below. For more detail, see the article **2003 Canadian definition** and pp. 43-44 of the ***ME/CFS: A Primer for Clinical Practitioners***. All quotations below are from the original medical paper.[1]

2003 Canadian case definition of ME/CFS

The definition first requires that other illnesses which could explain a patient's symptoms be ruled out.

To have ME/CFS, a patient must meet all four of these criteria:

- "the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain" explained below
- "have two or more neurological/cognitive manifestations"
- "one or more symptoms from the categories of autonomic, neuroendocrine and immune manifestations"
- "the illness persists for at least six months usually having a distinct onset, although it may be gradual." A "preliminary diagnosis may be possible earlier."

Thus, to be diagnosed the person must qualify under each and all of the following symptom categories:

- "Fatigue: The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that reduces activity level. Three months is appropriate for children."

- "Post-exertional malaise...There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional malaise...and/or pain and a tendency of other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period—usually 24 hours or longer."

- Sleep dysfunction: There is non-restorative sleep or decline in sleep quantity or dysregulation of normal sleep rhythms.

- Pain. "There is a significant degree of myalgia." The word means muscle pain, and is often the type of deep muscle pain experienced during the flu. "Pain can be experienced in the muscles/joints, and is often widespread and migratory in nature."

There are often headaches of a "new type, pattern or severity."

- "Neurological/Cognitive Manifestations"—To qualify in this category two or more of the listed symptoms must be present. Please see the specific list of symptoms in the actual document. They are grouped into:
  a) cognitive deficits including problems with memory, information processing, difficulties with thinking, and perceptual disturbances

  b) more classical neurological symptoms, including difficulty walking and muscle weakness; sensory hypersensitivity, including lower threshold for emotional overload.
- "Autonomic, Neuroendocrine and Immune Manifestations"—To qualify under this category the patient must have at least one symptom from two of the following three subcategories. Often a patient will have multiple symptoms:

  a) "Autonomic Manifestations: orthostatic intolerance, neurally-mediated hypotension; postural orthostatic tachycardia; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; difficulty breathing upon exertion; palpitations with or without cardiac arrhythmias."

  b) "Neuroendocrine Manifestations: loss of thermostatic stability—subnormal body temperature...sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of heat and cold, marked weight change—anorexia or abnormal appetite; loss of adaptability and worsening symptoms with stress."

  c) "Immune Manifestations: tender lymph nodes, recurrent sore throats, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and or chemicals

Reference

1. Carruthers *et al*. "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Definition, Diagnostic and Treatment Protocols," *Journal of Chronic Fatigue Syndrome* 11, No. 1 (2003): 18-126.

ME/CFS is a serious, usually chronic, multi-systemic, physical illness

Despite what you may have heard or been told, it is essential to know that ME/CFS is a *real and serious physical illness.*

The international medical researchers and clinicians who have done the best and most rigorous scientific work and treated thousands of patients are in full agreement that the illness is organic and not psychologically caused. Even the Centers for Disease Control and Prevention (CDC) has finally officially endorsed this view.

ME/CFS involves pathology in multiple systems of the body including: the immune system, the neurological system including the brain, the endocrine system, the cardiovascular system, as well as other systems and organs. A list of **common ME/CFS symptoms** makes this abundantly clear, as well as Dr. Anthony Komaroff's article **The Physical Basis of CFS**.

Please note: For those people who already have ME/CFS, if new symptoms develop during the course of the illness, don't just assume that they are new or variant symptoms of ME/CFS. People with this illness can develop new illnesses that require diagnosis and treatment. So, if new symptoms are present, err on the side of caution and see a physician to rule out another illness. If s/he seems unnecessarily casual about it, seek a second opinion. Dr. Rosalind Vallings of New Zealand ***has warned*** *that late diagnosis of cancer is a problem and patients need to report new symptoms and attend to having regular cancer screenings.*

What causes ME/CFS?

The cause of ME/CFS is not yet known, but current research shows strong evidence of immune, neuroendocrine, and circulatory system dysfunction. Research indicates that some parts of the immune system may be in an overactive state, while other parts of the system may be in an underactive state. There is convincing evidence that viruses or persistent viral fragments are associated with ME/CFS in many cases.

The authors of ***ME/CFS: A Primer for Clinical Practitioners*** (p. 43) have this to say about causality:

"ME/CFS usually occurs as sporadic (isolated) cases, but clusters of cases have occurred worldwide. Some outbreaks have affected large numbers of individuals in a particular community, hospital, or school. In sporadic cases, 20% of patients have another family member with the illness. These facts suggest that both genetic and environmental factors may contribute to the illness.

"ME/CFS frequently starts with acute, 'flu-like' symptoms and immune system changes found in ME/CFS are similar to immune system changes found in some viral infections. A number of infectious agents have been found more frequently in patients with ME/CFS than in the general population, but no infectious agent has been proven to be the cause.

"To avoid any possible contamination of the blood supply, patients with ME/CFS should refrain from donating blood.

"Occasionally, ME/CFS has been triggered by environmental toxins, the receipt of an immunizing injection, or surviving a major trauma.

"Although depression and anxiety may occur secondary to the illness, research studies have shown that ME/CFS and major depressive disorder
can be distinguished by behavioral, immunological and hormonal testing.

"The Centers for Disease Control and Prevention (CDC) recognizes CFS as an organic syndrome, not a psychiatric disorder."

What is the typical course of illness for ME/CFS?

ME/CFS may last many months or years. Symptoms may vary in severity and may wax and wane. A **25-year follow-up** of his patients by Dr. David Bell found that some of his patients recovered, but some of those who didn't became increasingly incapacitated. The **10+ Long-term CFS Study** found that the predominant symptoms became more neurological in patients ill more than fifteen years. More recent studies have found similar results.

Research has shown that there is no "typical" course of the illness. Both of the studies above found this. However, a 2014 New York multi-site study of ME/CFS patients ill more than five years found that temporary remissions, sometimes lengthy, were common.

While there is no known cure, many of the symptoms can be treated. Some patients show improvement over time, while others may show little improvement or a worsening of symptoms. The best strategy is for a patient to accept the fact of the illness and to develop coping skills that will make the situation as tolerable as possible. It is also important not to entirely give up on life, while waiting for the illness to resolve. It might not. See the section **Living with ME/CFS** for coping suggestions and the section on **Treatment**.

Finding a physician to make a proper and accurate diagnosis of ME/CFS

To obtain a proper and accurate diagnosis of ME/CFS, patients must have a physician who is sufficiently informed about the illness to make a proper and accurate diagnosis. Ideally s/he must be familiar enough with the 2003 Canadian and the current CDC definitions to apply them capably and correctly. So not only must the physician be able to diagnose ME/CFS, s/he must be a good diagnostician in terms of making differential diagnoses of neurological, endocrine, cardiovascular, and in some cases, psychiatric illness. Hence, a general practitioner may wish to consult one or more specialists.

Because ME/CFS is an illness about which physicians are still not sufficiently educated, patients must try to educate themselves to decrease the chances of misdiagnosis.

Occasionally the physician may be fairly well informed about ME/CFS and about how to diagnose the illness. In this case, the patient may be able to receive a proper diagnosis within a reasonable period of time. Unfortunately, experience shows that many doctors, both primary care physicians (PCPs) and specialists, are not yet well-informed about the illness, and so obtaining a diagnosis may take longer and be more difficult. The same is true about treatment and management; that is, the physician may be able to diagnose ME/CFS, yet not know how to manage it.

Many PCPs will be open-minded and will be willing to learn about the illness, especially if the physician knew the patient as a healthy person. In this case, the patient can give the doctor the 2003 Canadian and/or the current CDC definition (based on the 1994 definition), along with a few other medical or informational articles. The patient must be selective in the amount of material s/he gives to the doctor, since doctors are busy.

The doctor may consult with a colleague who knows more about the illness. If a PCP is confident in his or her ability to learn about the illness, s/he may make at least a tentative diagnosis of ME/CFS. If the doctor expresses uncertainty about knowing enough about ME/CFS for diagnosing, or seems unwilling to learn more about it, then request a referral to a physician more informed about the illness.

A specialist who is unfamiliar with ME/CFS can make a misdiagnosis as well as any other physician. Such misdiagnoses can often lead to many months of difficulty and, perhaps, improper treatment. To the extent possible, it is best to avoid these discouraging and painful detours that result from misdiagnosis. (Please see the section on **Differential Diagnoses**, and don't be shy in providing the linked articles or printouts to either a PCP or specialist, if appropriate.)

For more tips, see our section **Working with your Health Care Provider .** For assistance in finding a health care provider knowledgeable about ME/CFS, please **contact us (/services)** by phone or email.

What to do if a doctor insists "nothing" is wrong

Unfortunately, some patients have found that a previously concerned, friendly and helpful PCP may be less than helpful with an ME/CFS diagnostic process. The same can occur with any other doctor.

After an initial work-up, the PCP may say that s/he really can't find anything wrong, that the lab tests seem to be normal, and that the patient just really needs to rest, and then can resume a normal routine.

The patient may try this but finds it impossible because of the continuing symptoms, goes back to the doctor and reiterates the symptoms. The doctor begins to sound like a broken record while telling the patient "there is really nothing wrong." Both the patient and doctor can become very frustrated with this process. However, the patient must be persistent in reporting the symptoms to the physician.

What makes the situation especially difficult is that there are definitive, objective tests that show abnormalities in ME/CFS, but they are only done in a research setting—such as testing Natural Killer cell function or the RNase-L level in cells. Standard tests done in an illness work-up usually come back "normal" in ME/CFS, or just a little "off."

The doctor may become more distant and less friendly. S/he may imply the patient isn't physically ill; may state that the patient is under too much stress or have emotional problems and s/he may refer the patient to a psychiatrist. The doctor, rather than honestly expressing a lack of understanding, may begin to insist that as a doctor, s/he is in the best position to know what is going on.

Two things may be happening. First, when a doctor can't find anything physically wrong, the default clinical position is often that the illness might well be psychiatric.

Second, some doctors are overly concerned about being in control. So rather than admitting they cannot determine what is wrong, they need to feel they can make an actual diagnosis. Thus if the doctor can find no "objective" evidence (other than the sick patient in front of him/her), then s/he may conclude that the illness is psychiatric or due to "stress".

If this is the case, then the patient will clearly have to find another doctor who is informed and experienced enough to make a careful and objective diagnosis. If the patient is finally diagnosed properly—whether the diagnosis is ME/CFS or not—then the patient will have to decide whether s/he can still work with the PCP. Perhaps, after another, better-informed doctor makes the correct diagnosis, the PCP will accept the diagnosis and be willing to again engage in a genuinely helpful patient/doctor relationship.

Some patients find that their PCP is very good for routine and other medical issues, while at the same time they see a better-informed physician for ME/CFS treatment. However, this is not the best arrangement, since ME/CFS cannot be separated from the patient's overall health. Should another illness develop, only a doctor who is keeping up with the patient's entire clinical picture is in the best position to recognize a new and separate problem.

Is there a psychiatric disorder?

One of the thornier problems in the diagnosis of ME/CFS is whether the patient has ME/CFS or a psychiatric disorder. In some cases, there can be a genuine need to make a differential diagnosis between ME/CFS and a psychiatric disorder. Here the most important diagnostic step to differentiate primary from secondary (post-illness) onset is the patient's history. If not carefully and thoroughly done, the physician may miss what is a simple but very imporant differentiation. Taking an adequate history requires more than a few minutes!

In cases where ME/CFS is already established, there can be difficult, sometimes very difficult, emotional problems coping with and living with this illness. There can be definite secondary depression or anxiety secondary to having to deal with the very real problems caused by the illness.

A properly trained mental health professional who is knowledgeable about ME/CFS can be supportive and additionally help a patient figure out ways to cope with the illness. In cases in which the patient becomes severely depressed or even suicidal, then such mental health care becomes imperative, and a physician would be negligent in not making a referral.

However, there is all too often a psychiatric referral for differential diagnosis that is made out of ignorance or for biased reasons. If the PCP is making the referral because of some real question in his/her mind of whether the illness is ME/CFS or psychiatric, the patient must carefully consider the PCP's reasoning and explanation for the referral.

If there is some genuine doubt that the patient is not physically ill or that the primary cause for physical symptoms is psychological (a rarity of cases), then proper differential diagnosis would call for a psychiatric consult—*but only to a psychiatrist or psychologist who is well informed about ME/CFS.*

All too often referrals to psychiatrists and other mental health professionals result in blatant misdiagnoses that can become a harmful and counter-productive problem that will take much effort to rectify. If the patient finds a psychiatric consult to be unhelpful or "psychologically-biased" concerning physical symptoms, then the patient should leave.

Make sure to see a mental health professional who is properly informed about ME/CFS. An example of such an instance might be that a patient is applying for Social Security disability and the PCP has indicated some concern that the patient suffers from depression rather than ME/CFS. Then, a properly educated mental health professional would set the record straight that the patient does in fact have ME/CFS.

For more information about the differential diagnosis of ME/CFS vs. psychiatric disorder, see our Differential Diagnosis (/differential-diagnosis?start=5) section.

Summary of elements necessary to obtain a proper and accurate diagnosis of ME/CFS

- The patient should learn as much as possible about how a proper and accurate diagnosis of ME/CFS is made: what medical Diagnostic Criteria are most accurate and in current use. (*We recommend the 2003 Canadian definition*.) The patient, his/her family and significant others must be in a position to evaluate if the physician is properly diagnosing the illnesses, or if a misdiagnosis is occurring. *A patient cannot be his or her own doctor—not only is this impossible, it is hazardous—but an educated patient can assist the physician and be, as much as possible, a partner with him or her.* This is difficult when the patient is very sick, so perhaps a family member or friend can help with this. Unfortunately, with so much misinformation about these illnesses, even among many fine doctors, the patient must be able to evaluate what is going on. Moreover, by being informed, the patient can provide the physician, when appropriate, with copies of the Diagnostic Criteria and other information on the illnesses. Many doctors who are not fully informed about the illnesses will appreciate receiving scientific and medical information that will assist them in diagnosing and treating their patients.

- The patient must be able to describe his/her illness as carefully and accurately as possible to the physician—the symptoms of the illness, how severe they are, do they come and go; how did the illness begin, how does it occur from day-to-day and week-to-week. The physician needs to be able to spend the necessary time evaluating the illness and eliciting from the patient the information needed to make a careful diagnosis. It is crucial that the patient is as succinct and well-organized as possible during the visit. This requires homework before the appointment, perhaps with the assistance of a family member or friend. Without that preparation on the part of the patient, the physician can't do his/her job.
- The patient needs to have a doctor who is capable of making an accurate and proper diagnosis. The physician should be sufficiently informed as to the actual nature of the illness and how the proper diagnostic criteria are correctly applied.

The patient and doctors may find it helpful to use the Activity Log in Appendix D p. 39 and the Functional Capacity Scale in Appendix C p. 38 of ***ME/CFS: A Primer for Clinical Practitioners***