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Jill McLaughlin has been an ME/CFS advocate since 1996; two of her three daughters have ME/CFS. She is the author of numerous articles on ME/CFS, was the Executive Director for the National CFIDS Foundation for six years, and works in membership coordination for the IACFS (International Association for Chronic Fatigue Syndrome).

We do not need a name change or new name. We have the name of a well recognized illness with a 50 year history in the medical literature (and a current clinical case definition). In fact, patients do not like the name change that was foisted on them in 1988 - from Myalgic Encephalomyelitis to chronic fatigue syndrome.□□

Excerpts from *A Rose By Any Other Name*
by Dr. E.G. Dowsett

"ME has already been called the 'Disease of a Thousand Names'..."

"Historical Background: *The earliest definitions were brief but succinct, based on clinical observation and accompanied by a checklist of symptoms. WALLIS (1995) provided a concise list with appropriate variations for children and adolescents, while RAMSAY (1956) introduced the descriptive term (Myalgic encephalomyelitis), which has stood the test of time over half a century in the UK, Europe, Canada and Australasia."*

"Fatigue States: *These definitions first arose in the USA following the 1984 Lake Tahoe epidemic (which was misattributed to a Herpes Virus infection). Both the earliest definition (HOLMES et al, 1988) and its revision (FUKUDA, 1994) elevated tonsillitis, glandular enlargement and fatigue to unreal importance while overlooking the characteristic encephalitic features of the genuine illness."*

"What Are the Facts: *The tools we can use today to study the brain offer possibilities which were unimaginable 50 years ago². These include Molecular Biology: for example PCR – a microbiological technique capable of amplifying and identifying minute fragments of viral genes, hidden away in internal organs (such as brain, heart or muscle ³) while a test for rapid diagnosis (within five hours) is currently available. These tests indicate that viruses from the polio group, or related to it, are involved both in the late effects of ME and the Post Polio Syndrome ⁴. Brain Imaging: the use of CT, MRI, SPECT and PET scans clearly indicates that metabolic dysfunction in the brain stem and the spinal nerve radiations which transverse it, are initially associated with viral (inflammatory) damage and are the major cause of the cardinal symptoms of ME – central fatigue, stress induced weakness, autonomic nervous dysfunction and the breakdown of homeostasis over hormonal and other vital functions⁵."*

"Conclusion: *Modern technology has now served to confirm and to detail the meticulous clinical and scientific observations made about ME before 1988! We can rest assured that this serious disability can arise (like polio) from an initially trivial infection which has epidemic and pandemic potential but we need to give further thought to any name change. We should, instead, be making maximum use of modern and effective means of diagnosis, prevention and management."*

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What is ME?

What is CFS?

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome:

An Informational Guidebook for Doctors & Patients

by
Jill McLaughlin

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What is CFS? What is ME?

The term Chronic Fatigue Syndrome (CFS) was introduced in 1988 to describe medically unexplained, persistent or relapsing fatigue of new onset. CFS has come to include what has historically been known as Myalgic Encephalomyelitis (ME).

CFS represents a broad diagnostic category and selects a heterogeneous (mixed) patient population, amalgamating disparate health problems that contain "fatigue" under the umbrella term CFS. Some patient groups adopted the term Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) to differentiate it from idiopathic chronic fatigue.

M.E. is a more specific and appropriate diagnosis than chronic fatigue syndrome, as it describes a specific condition with muscle and neurological symptoms, not only the ubiquitous symptom of fatigue.

M.E. is a distinct clinical entity that can be clearly defined by observable physical signs and characteristic features (not merely by exclusion), the most distinctive being incapacitating exhaustion after even minimal exertion, and prolonged recovery time. More specifically, the fatigue in M.E. is exertion related (vs. "tired all the time") with a significantly prolonged recovery time, and all symptoms can be exacerbated by levels of physical, cognitive, sensory or emotional stress that would have been of no consequence prior to the illness onset.

M.E. is a systemic disease with many systemic features, but characterized primarily by central nervous system (CNS) dysfunction, of which fatigue, sleep disorders, autonomic dysfunction, cognitive dysfunction, endocrine dysfunction, proprioceptive dysfunction, sensory dysfunction, etc., are among the many and varied manifestations. It is also characterized by what may be a marked variation and fluctuation of symptoms, both in occurrence and intensity.

CFS and M.E. are currently classified in the WHO ICD-10 as neurological disorders, code G.93.3 "Diseases of the Nervous System - Other Disorders of the Brain and Central Nervous System." The USA still uses the modified version of the ICD-9-CM for insurance purposes, in which CFS and M.E. are listed in the neurological chapter under code 323.9.

(Note: CFS is also listed in the ICD-9-CM as 780.71, Symptoms, Signs and Ill Defined Conditions, Fatiguing Illnesses.)

What's in a name?

Terminology and usage is beyond preference or semantics, as it is impossible to write about any illness, particularly one so complex, without attempting to define and understand the various terms used to describe it.

Currently both names/descriptions may be used, or sometimes may be used interchangeably, which has led to a great deal of confusion. Overall CFS/CFIDS is used in the U.S., while M.E. is still preferred by most of Europe, Canada, Australia and New Zealand.

Dr. Charles Lapp, board member of the American Association of Chronic Fatigue syndrome (AACFS) and member of a federal HHS CFS advisory committee, states *"One thing that we all seem to agree on is that the word 'fatigue' needs to be removed from the name of the illness we call 'chronic fatigue syndrome.' Just tell somebody that you have chronic fatigue syndrome, and the first retort is, 'Oh I have that too; I'm just so tired.' The term 'chronic fatigue,' while descriptive of the most common symptom of this illness, is so vague and banal that it seems derisive and derogatory. The 'fatigue' of this illness is so much more than just 'tiredness.' In fact there is no word in the English lexicon that describes the lack of stamina, the paucity of energy, the absolute malaise and turpitude that accompanies this illness."*

One symptom should not be the name, especially one so non-specific and non-definable as fatigue, which is shared by nearly all illnesses both physical (neurological, autoimmune, infectious, malignancies, etc.) and psychiatric, as well as being a normal physiological state; nor should fatigue be the defining feature, nor the basis for researching the illness. It is impossible to convey the seriousness of an illness whose name merely denotes "tiredness."

The prominent association of fatigue with psychiatric disorders has greatly contributed to the erroneous psychological attributions of the illness, much to the detriment of patients.

This has led to the trivialization of the illness as little more than a manageable, unexplained fatigue state (rather than the prominent more specific and debilitating neurological features of M.E), and the misperception that it may be treatable by little more than counseling, OTC medications, antidepressants and lifestyle changes.

Until the name/definition issues are resolved, a general worldwide consensus has been the interim adoption of the term ME/CFS (to specify what some have recognized and referred to more specifically as "strictly defined CFS" which is what prior to 1988 was recognized as M.E.)

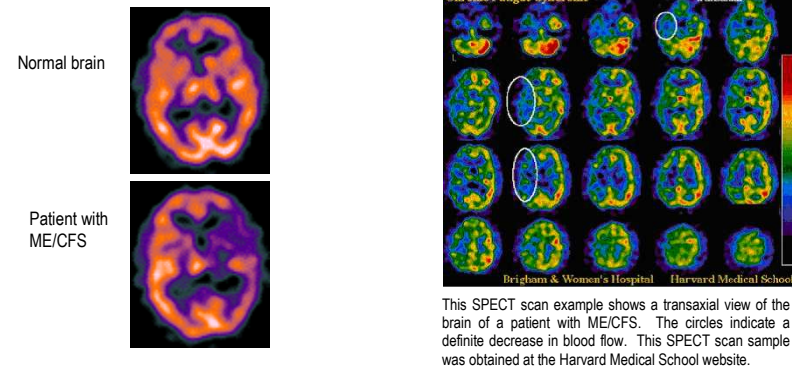
ME/CFS is a serious, complex illness with numerous systemic features. Based on clinical and scientific evidence, ME/CFS may be characterized as a CNS dysfunction, which offers the most plausible explanation for the diverse physical and neuropsychiatric symptoms, of which fatigue, neurally mediated hypotension (NMH), sleep disorders, etc., are among the many and varied manifestations.

and 610 (50%) indicated that it made their condition worse.

This was the highest negative rating of any of the pharmacological or non-pharmacological interventions covered in the questionnaire (and may explain the high drop out rates found in some of these programs).

Exercise has been shown to be an ineffective form of treatment, while it has also been confirmed that there may be ongoing neurological, endocrine, immunological, and cardiovascular abnormalities that are causing the symptoms of ME/CFS. Exercise will not treat or improve these abnormalities, and in fact will exacerbate symptoms that are caused by such abnormalities. (Dr. A. Martin Lerner discovered that some patients had persistent viral infections in the heart, causing left-ventricular dysfunction, resulting in exercise intolerance. Exercise worsens the cardiac dysfunction.)

Even minor activity, either physical or mental, may cause a significant worsening of symptoms. The recommended management for ME/CFS is not exercise but "activity" management (sometimes referred to as pacing), which is to conserve energy, not to expend it. These are very different concepts, and pacing is intended to prevent overexertion and relapse, not for improvement. On average, ME/CFS patients have been shown to be functioning dangerously close to their energy limits, and increasing activity is counter-productive. If even trivial activity can exacerbate symptoms, then exercise is not an effective treatment.



This SPECT scan example shows a transaxial view of the brain of a patient with ME/CFS. The circles indicate a definite decrease in blood flow. This SPECT scan sample was obtained at the Harvard Medical School website.

"SPECT scans show anterolateral and dorsolateral hypoperfusion, the right hemisphere worse than the left. The right hemisphere deals mostly with novel situations and uses Norepinephrine. Norepinephrine is crucial to cognitive novelty. The left hemisphere deals mostly with repetitive, well-routined, pre-learned activities and uses mainly dopamine. Dopamine is critical to cognitive routinization. Flu-like illnesses are known to deplete brain Norepinephrine. Regional cerebral blood flow is consistently found to decrease after exercise or any activity that makes the patient worse, for example doing calculations.

PET scans show activation of the dorsolateral prefrontal cortex along with decreased regional cerebral blood flow to the left angular gyrus, part of the neural network involved with tasks that require "willed action". Hypoperfusion and malfunctioning of the inferior parietal cortex leads to inappropriate sensations, behavior and emotions." *Betrayal By The Brain: The Neurological Basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome and Related Neural Network Disorders.* Dr. Jay Goldstein

ME/CFS and Children

Few pediatric studies have been done, yet it is well established that children and adolescents get ME/CFS. Minimal attention has been paid to critical features of ME/CFS in children and is thus often unrecognized in children. Children with ME/CFS are frequently dismissed as depressed or school phobic, and thus remain unable to receive proper care or accommodations for their illness.

The effects can be devastating in children, resulting in serious disruption of their education and social development. Research conducted in the UK on a large school population showed that 51% of all children on long-term sickness absence had ME/CFS, overturning the myth that it is extremely rare in children. A national report done by the UK Department of Health clearly states that all children who are moderately to severely affected will require home tutoring or distance learning and should not be expected to attend school, which can cause severe relapses.

CBT

CBT (Cognitive Behavioral Therapy) is a form of psychotherapy focused primarily on changing the way we think in order to reduce the understandable feelings of fear, depression and anxiety associated with chronic illnesses.

CBT has often been misrepresented, claiming that it is an effective treatment for the condition as a whole□ which goes well beyond the evidence.

In terms of scientific evidence, the CBT trials have generally not included measures of symptoms other than fatigue and emotional distress. These trials have little relationship to patients with organic immunological and neurological abnormalities. While there may be improvement in emotional distress, CBT does not improve overall activity or physical functioning.

The complexity of CBT studies, their varied inclusion and exclusion criteria, issues of proper blinding, and the subjective means used for most evaluations seriously questions the validity of their results.

The literature is replete with psychiatric studies on CFS (often lumped in with chronic fatigue states caused by other illnesses) that have no bearing on ME/CFS. It is not possible to effectively treat any neurological condition by using passive forms of psychological counseling.

The Exercise Question

According to Dr. Melvin Ramsey's seminal work on M.E., □*The degree of physical incapacity varies greatly, but the dominant clinical feature of profound fatigue is directly related the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis.*□

It has been demonstrated that graded exercise was either of little or no use to the majority of patients, and that the use of graded exercise on the severely affected was indeed harmful. In a British study, 1,214 of 2,338 patients had tried graded exercise. Of these, 417 found it to be helpful, 197 reported no change

Brief History of ME/CFS

M.E. has been documented in the medical literature since 1934 in both epidemic and sporadic forms and has been formally classified by the World Health Organization (WHO) as a neurological disorder since 1969.

There have been many recorded outbreaks of M.E. during the 20th century, which in the U.S. were initially referred to epidemic neuromyasthenia. In 1959 a comprehensive review paper was published by Dr. Donald Henderson (a CDC epidemiologist) and Dr. Alexis Shelakov (an NIH epidemiologist) in the New England Journal of Medicine describing several outbreaks. Dr. Henderson noted: □*The pattern of the epidemic, the absence of any common exposure factors and the high incidence among medical and hospital personnel were consistent only with an infectious disease transmitted from person to person.*□

In 1988, what was historically known both as myalgic encephalomyelitis (M.E.) and as the well-documented epidemic neuromyasthenia was renamed Chronic Fatigue Syndrome by a panel convened under the aegis of the CDC. CFS was redefined in 1994 and now has become a broad diagnostic category and covers nearly anything with profound, chronic, unexplained fatigue. Little epidemiology has been done since, as it is not feasible to confirm clusters of fatigue.

How is ME/CFS diagnosed?

An international panel of experts under the auspices of HealthCanada recently developed a Clinical Consensus Definition: *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols, Journal of Chronic Fatigue Syndrome, Vol. 11 (1) 2003*. This definition is far superior to the various other CFS definitions, and has been welcomed internationally. It includes the hallmark features of M.E. (optional in the CFS definition)□ post-exertional malaise, neurological and cardiovascular symptoms□ which more accurately represent the true symptomatology and pathophysiology of the illness than other current (fatigue based) definitions. This definition represents the current best practice guidelines for diagnosing and managing ME/CFS.

Dr. Melvin Ramsay, pioneer UK researcher and clinician, posits this description of M.E.: 1) Muscle myopathy, which Ramsay describes as a delay in muscle recovery after exercise. 2) Circulatory impairment including intolerance to temperature extremes. 3) Cerebral (brain) dysfunction including problems with memory and concentration, sleep disturbances, noise intolerance, palpitations and tachycardia.

In the US, CFS is diagnosed using the Fukuda (1994) definition which requires that the patient meet the following criteria with no alternative medical or psychiatric explanation:

1) Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset, is not the result of ongoing exertion, is not substantially alleviated by rest and results in a substantial reduction in previous levels of functioning. 2) The concurrent occurrence of four or more of the following symptoms: substantial impairment of short-term memory or concentration, sore throat, tender lymph nodes, muscle pain, multi-joint pain without redness or swelling, headaches of a new type, pattern or severity, unrefreshing sleep, post-

unrefreshing sleep, post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more months of illness and must not have predated the fatigue.

Patients may fulfill the loose Fukuda criteria and have fatiguing disorders other than ME/CFS. These vague criteria may include those with fatigue due to primary sleep disorders, nutritional deficiencies, stress, psychiatric conditions and many other diseases. This [Fukuda] definition was developed for research purposes but has proven inadequate for both research and clinical purposes. Its focus on non-specific fatigue which creates difficulties in distinguishing the pathological myopathy, encephalopathy and immune dysfunction in ME/CFS as discrete from ordinary fatigue or other fatiguing illnesses. Thus, practitioners are turning toward the use of the Canadian Clinical Case Definition, as well as Ramsey's historic definition of M.E., while the US works to address the shortcomings of the Fukuda definition.

Other Symptoms & Characteristics

Symptoms also frequently include pain, vertigo (dizziness), visual disturbances, photophobia, spacial disorientation, disequilibrium, nausea, paresthesias (numbness and tingling), dyspnea (shortness of breath), emotional lability (mood swings), tachycardia, sleep disorders (hypersomnia or insomnia), low-grade fever, intolerance to alcohol, seizure activity.

Fragmented sleep (periods of wakefulness throughout the sleep period) and lack of deep-stage sleep are very common. True insomnia (inability to fall asleep) is uncommon, although patients may have delayed sleep onset because of a disrupted circadian rhythm (resulting in reversal of nighttime sleep pattern).

Neurocognitive dysfunction may include cognitive, motor and perceptual disturbances. The cognitive dysfunction may be more variable but may be pronounced, and is sometimes referred to as "brain fog," or confusion. It also includes slow information processing speed, trouble with speaking, writing, reading and short-term memory.

There may be an "overload phenomenon," where patients may be very sensitive to light, sounds, odors. The variable sensory, cognitive, emotional or motor overload may precipitate a "crash," where the patient experiences a severe, incapacitating physical/mental exhaustion and weakness, and worsening of other symptoms.

Similar Medical Conditions

ME/CFS is similar to other illnesses such as multiple sclerosis, lupus, Lyme disease, mononucleosis, Gulf War Syndrome. ME/CFS may overlap or co-exist with fibromyalgia, multiple chemical sensitivities, irritable bowel syndrome.

However, these may co-exist with other conditions as well and are viewed as separate entities which stand on their own, regardless of whether a person has other medical problems. Even though there are similarities or overlap does not mean that they represent the same etiological or pathobiological process.

The National CFIDS Foundation has a Memorial list of ME/CFS patients who have died, the most recognizable causes being cancer and heart disease (a paper is under review). After decades of illness, death is known to occur from end-stage organ damage. Many patients are only in their middle forties and fifties.

Treatment

Treatment has been palliative at best, based on trial and error application of anecdotal evidence, and has been mostly limited to the relief of specific symptoms. This has been largely inadequate. ME/CFS patients may be extremely sensitive to many medications, so only low doses should be given initially and still may produce intolerable side effects.

The testing and recognition of underlying abnormalities offers the most effective treatment. For example, treating hypothalamic dysfunction, which produces poor sleep, low hormone levels, and treating the effects of immune dysfunction/chronic infections (immune modulation to shift from Th2 to Th1 predominance, enhance NK cell activity, reduce pro-inflammatory cytokines, antivirals to reduce viral reactivation etc.) have proven the most successful.

There are currently no FDA-approved medications for use in treating ME/CFS. There are, however, a number of medications that may be helpful, even though some are recommended for effects that may be unrelated to their primary use. These include antifungals, antihistamines, antivirals, antibiotics, CNS depressants, immunoglobulins, cardiac medications, anti-inflammatories, anticonvulsants, expectorants and antidepressants.

Vaccine Recommendations

ME/CFS patients should generally not be offered live vaccines because of risk of relapse.

Flu vaccinations are generally not recommended to persons with ME/CFS unless patients have tolerated them well in the past or have other medical complications in addition to ME/CFS. Flu vaccines may cause serious relapses, and many patients fail to sero-convert (develop antibodies) to the vaccination. Thus, patients may have side effects in addition to a relapse of symptoms, but may not even develop immunity.

Since smallpox vaccine is a live vaccinia virus, many experts recommend that persons with ME/CFS not take smallpox vaccine, due to high incidence of immune dysfunction, autoimmune phenomenon, and hypogammaglobulinemia.

Economic Burden

ME/CFS costs the U.S. more than \$9 billion each year in lost productivity, or about \$20,000 per person annually, not even including healthcare costs, according to a CDC study published in the journal *Cost Effectiveness and Resource Allocation*. About a quarter of those with chronic fatigue syndrome, or ME/CFS, aren't able to work at all, and those who do continue to work lose about one-third of their income, the report said.

Prevalence and Risk Factors

Recent data has established the importance of ME/CFS as a serious public health concern. A Chicago study estimated that 800,000 adults in the U.S. have ME/CFS. More importantly, *90% have never been appropriately diagnosed.* This is a public health crisis.

Initial research suggested that ME/CFS was a relatively rare disorder and affected mainly upper middle class Caucasian women. For some time there were even disputes in medical circles about whether ME/CFS existed or if it was a "real" illness, even though it is formally recognized by the CDC, NIH, SSA, WHO. It was initially disparagingly dubbed "Yuppie flu," giving the impression that it affected mainly overachievers who couldn't handle stress and burned out, which hardly seemed to warrant much attention or concern.

But in truth, ME/CFS is not limited to any specific race, age or socioeconomic group. Contrary to the "yuppie flu" myth, this study also showed the illness to be wide-spread in low-income and minority communities. It is most common among minorities, with Latinos and Mexican Americans exhibiting higher rates than Caucasians.

Onset and Prognosis

The clinical course of ME/CFS varies considerably. There is a full spectrum of disease severity, with some patients being mildly affected while others are in wheelchairs or completely bedridden. The clinical outcome of ME/CFS usually takes one of three courses: recovery/improvement, relapsing/remitting course, and permanent incapacity or progressive deterioration of symptoms. Studies have shown that recovery is uncommon, with only 4% of patients recovering and 39% showing some symptom improvement after four years.

Those who obtain an early diagnosis, and receive appropriate care and management, tend to be the ones who make the most significant progress.

Australian researchers found that ME/CFS patients had more dysfunction than those with M.S., that the degree of impairment was more severe than in end stage renal and heart disease, and that only in terminally ill cancer and stroke patients was the sickness impact profile (SIP) higher than in ME/CFS.

Twenty five percent of the severely affected are home or bed-bound, many are unable to manage a visit to the doctor's office and thus are often unable to receive any medical care or services. Many are abandoned by the medical community, their family and friends and society in general, become isolated and remain ignored and invisible.

ME/CFS clinician and researcher Dr. Paul Cheney stated before an FDA Scientific Advisory Committee: *"The worst cases have both an MS-like and an AIDS-like clinical appearance. The most difficult thing to treat is the severe pain. Most have abnormal neurological examination. Eighty percent of cases are unable to work or attend school. We admit regularly to hospitals with an inability to care for self."*

Suicide rates are high and seem to be related to the current climate of disbelief and rejection and inability to receive adequate support and services.

Is ME/CFS a psychiatric condition?

Although some symptoms may be similar, ME/CFS is not a psychiatric illness. There are several objective findings that differentiate ME/CFS from psychiatric conditions and indicate that it is biologically, not psychologically determined.

According to Harvard University professor Dr. Anthony Komaroff: *"In summary, there is now considerable evidence of an underlying biological process in most patients [which] is inconsistent with the hypothesis that [the illness] involves symptoms that are only imagined or amplified because of underlying psychiatric distress. It is time to put that hypothesis to rest."*

The prevalence rates of clinically significant depression in patients with CFS are not much different from those reported in other medically ill populations.

Abnormalities in ME/CFS

SPECT scans have demonstrated decreased cerebral blood flow; PET scans have shown decreased brain metabolism (see images on page 11); MRI scans have shown the presence of small white matter lesions. These abnormalities have been shown to correlate with clinical status. The abnormalities in ME/CFS patients most closely resemble those seen in AIDS encephalopathy.

Neuroendocrine abnormalities have been found in the hypothalamic-pituitary-adrenal (HPA) axis. Hypothalamic dysfunction causes decreased cortisol; thus patients react extremely adversely to stress.

Autonomic nervous system dysfunction includes orthostatic intolerance, neurally-mediated hypotension (NMH) and postural tachycardia syndrome. Many patients have low blood volume.

The immune system abnormalities mimic the immune pattern seen in viral infections. Specific findings include increased numbers of activated cytotoxic T cells, low natural killer cell function, and elevated immune complexes. A large University of Miami study found that the array of immunological defects suggest that ME/CFS is a form of acquired immunodeficiency.

A more specific immune system abnormality has been discovered in ME/CFS of increased activity and dysfunction of the 2-5A RNase-L antiviral pathway in lymphocytes. The dysregulation of the RNase-L pathway supports the hypothesis that viral infection may play a role in the pathogenesis of the illness. Patients with ME/CFS were very different from patients with major depression, fibromyalgia or healthy controls.

Sub-optimal cardiac function and abnormal cardiovascular responses have also been demonstrated. One study found left-ventricular dysfunction following exertion and orthostatic stress in patients with ME/CFS, and that the heart failed to pump enough blood following exertion and upright posture. Dr. A. Martin Lerner discovered persistent viral infection in the heart, causing left-ventricular dysfunction, resulting in exercise intolerance. (Exercise, in turn, worsens the cardiac dysfunction.) The disease in the early stages is consistent with a dilated cardiomyopathy that in later stages might result in progressive, end-stage dilated cardiomyopathy, a type of heart failure.

Abnormal laboratory values do occur among ME/CFS patients. These may include: Immune complexes, Immunoglobulin G, low level Antinuclear antibody titer, Alkaline phosphatase, Cholesterol, Lactate dehydrogenase, atypical lymphocyte count.

These tests may support a diagnosis of ME/CFS, although they lack sufficient sensitivity to be considered diagnostic tests, but can be used as objective markers of illness to support disability claims.

More recently, the University of Hawaii discovered the occurrence of an endogenous lipid, similar in structure to ciguatoxin, in ME/CFS. The chronic phase lipids (CLP) may be comparable to "acute phase proteins" such as C-reactive protein, which increase in diseases such as inflammation and trauma. The test for CPL may be used to confirm the diagnosis. The testing procedure is on the NCF website at <http://www.ncf-net.org/>

Infectious Agents

It has been well established that fatigue occurs in infectious illnesses. Many patients suffer from sore throats, fever, tender lymph nodes, which accompany diseases caused by infectious agents. Several retrospective studies have shown that infectious agents play an important role in the onset and maintenance of ME/CFS. The role of infections remains unclear as to whether they may be causative, co-factor or opportunistic.

ME/CFS has been associated with several infectious agents including Mycoplasma, Rickettsia, Chlamydia, Borrelia. Several viruses have been associated with ME/CFS, including: herpes virus, particularly human herpes virus 6 (HHV-6), Epstein-Barr virus (EBV, which causes infectious mononucleosis), Cytomegalovirus and Coxsackie viruses. Indirect immunological evidence also supports the role of persistent viral infection.

These infections have been found to play an important role in ME/CFS, and antimicrobial therapy to suppress chronic infections has resulted in improvement. Whether or not they are causal, these agents may contribute to the morbidity and warrant appropriate testing and treatment.

What causes ME/CFS?

The precise cause is unknown, but published studies continue to demonstrate that the basis lies in abnormalities of the central nervous system (CNS) and immune system, both of which influence and alter the function of the other. A large study of the Incline Village, Nevada outbreak in the early 1980's reported that ME/CFS represents "an immunologically mediated inflammatory process of the CNS."

Due to its similarity to chronic mononucleosis, CFS was initially thought to be caused by a virus infection, most probably Epstein-Barr virus (EBV). However EBV activation (along with reactivation of other latent viruses) is now considered a consequence of an altered immune system, rather than the cause of ME/CFS.

Based on physical and clinical evidence, many experts believe that viruses are associated with ME/CFS and may be involved in causing the illness. There is evidence from several controlled studies of the reactivation of several chronic viral infections in ME/CFS. ME/CFS has been documented following a variety of acute infections with viruses (such as following acute infectious mononucleosis), bacteria (such as following properly-treated Lyme disease), and other microbial infections (such as following Q fever).

Dr. Anthony Komaroff, international ME/CFS expert and Harvard researcher, notes the relationship between the CNS abnormalities and infection, for which there is considerable evidence. The article published in the Journal of Internal Medicine states: "*one interesting hypothesis that links infection with CNS dysfunction is the possibility of a chronic viral encephalitis as an initiator of a process that leads to CFS. It is known that viruses in animals and humans can affect the HPA axis, thus making infectious agents that cause CNS disturbances of particular interest.*"

CFS research is conducted on many international governmental and independent fronts, as well as at the CDC by the Division of Viral and Rickettsial Diseases, National Center for Infectious Diseases.

Is ME/CFS contagious?

Thorough transmissibility studies have not been conducted. ME/CFS has been reported in multiple family members. Some studies have shown genetic linkages, however, genetic basis is not consistent with the epidemiology of ME/CFS. Genetic diseases slowly increase in the population over time, not as a sudden explosion of cases, as happened with ME/CFS in the early-mid 1980's.

There have been numerous outbreaks of M.E. worldwide. A large epidemiological investigation was conducted on a 1956 outbreak in Punta Gorda, Florida by Chief of CDC's Epidemic Intelligence Service, Dr. D.A. Henderson (who is revered for spearheading the successful effort to eliminate smallpox). According to Dr. Henderson, "*The pattern of the epidemic, the apparent absence of any common exposure factors and the high incidence of illness among medical and hospital personnel were consistent only with an infectious disease transmitted from person to person. We were able to postulate the general nature of the micro-organism. It was probably a virus.*"

According to the Red Cross, patients with autoimmune disease, including systemic lupus erythematosus and multiple sclerosis, are not eligible to donate blood. Chronic fatigue syndrome appears under chronic illnesses. Blood donation from most chronic illnesses patients is acceptable as long as they feel well. Chronic fatigue syndrome, fibromyalgia, rheumatoid arthritis, ulcerative colitis and Crohn's Disease are not specific disqualifications.

A CDC official advised an inquiring ME/CFS patient to refrain from donating blood or organs until the cause or mode of transmission is better understood. It has been shown that patients may harbor infectious agents in their blood. Blood donation may also exacerbate symptoms due to low blood volume, which has been detected and studied in ME/CFS patients.