

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

Why the disease category of 'CFS' must be abandoned

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The terms Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (M.E.) are not synonymous. However, to understand anything at all about 'CFS' one must first be aware of the history of M.E.

A brief history of Myalgic Encephalomyelitis up to 1988

The illness we now know as Myalgic Encephalomyelitis is not a new illness. M.E. is thought to have existed for centuries. (Hyde 1998, [Online]) (Dowsett 1999a, [Online])

One of the most fundamental facts about M.E. throughout its history is that it occurs in epidemics. This fact conveys, among other things, the infectious and contagious nature of the disease (Hyde 1998, [Online]). The usual incubation period of the virus infection involved is 4-7 days. There is a history of over sixty recorded outbreaks of the illness going back to 1934 when an epidemic of what seemed at first to be poliomyelitis was reported in Los Angeles. As with many of the other M.E. outbreaks the Los Angeles outbreak occurred during a local polio epidemic.

The presenting illness resembled polio and so for some years the illness was considered to be a variant of polio and classified as 'Atypical poliomyelitis' or 'Non-paralytic polio' (TCJRME 2007, [Online]) (Hyde 1998, [Online]) (Hyde 2006, [Online]). Many early outbreaks of M.E. were also individually named for their locations and so we also have outbreaks known as Tapanui flu in New Zealand, Akureyri or Icelandic disease in Iceland, Royal Free Disease in the UK, and so on. M.E. was also known as 'Atypical multiple sclerosis' at one time, because of the similarities between M.E. and MS (TCJRME 2007, [Online]) (Hyde 1998, [Online]).

A review of early M.E. outbreaks found that clinical symptoms were consistent in over sixty recorded epidemics spread all over the world (Hyde 1998, [Online]). Despite the different names being used, these were repeated outbreaks of the same illness. It was also confirmed that the epidemic cases of M.E., and the sporadic cases of M.E. each represented the same illness (Hyde 2006, [Online]) (Dowsett 1999a, [Online]).

In 1956 the name Myalgic Encephalomyelitis was created. The term was invented jointly by Dr A Melvin Ramsay who coined this name in relation to the Royal Free Hospital epidemics that occurred in London in 1955 - 1957 and by Dr John Richardson who observed the same type of illness in his rural practice in Newcastle-upon-Tyne area during the same period. It was obvious to these physicians that they were dealing with the consequences of an epidemic and endemic infectious neurological disease (Hyde 1998, [Online]) (Hyde 2006, [Online]). The term Myalgic Encephalomyelitis means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation (Hyde 2006, [Online]). As M.E. expert Dr Byron Hyde writes:

The reason why these physicians were so sure that they were dealing with an inflammatory illness of the brain is that they examined patients in both epidemic and endemic situations with this curious diffuse brain injury. In the epidemic situation with patients falling acutely ill and in some cases dying, autopsies were performed and the diffuse inflammatory brain changes are on record (2006, [Online]).

In 1957, the Wallis description of M.E. was created. In 1959 Sir Donald Acheson (a former UK Chief Medical Officer) conducted a major review of M.E. (Hooper et al. 2001, [Online]). In 1959 Dr. Donald Henderson (a CDC epidemiologist) and Dr. Alexis Shelakov (a NIH epidemiologist), published a comprehensive review paper 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' (McLaughlin 2004, [Online]). In 1962 the distinguished neurologist Lord Brain included M.E. in the standard textbook of neurology. In recognition of the large body of compelling research that was available, M.E. was formally classified as an organic disease of the central nervous system in the World Health Organisation's International Classification of Diseases in 1969 with the code G.93.3. In 1978 the Royal Society of Medicine held a symposium on Myalgic Encephalomyelitis at which M.E. was accepted as a distinct entity. The symposium proceedings were published in The Postgraduate Medical Journal later that same year. The Ramsay case description of M.E. was published in 1981 (Hooper et al. 2001, [Online]).

Myalgic Encephalomyelitis from 1988 to the present

www.hfme.org/cfsmustbeabandoned.htm

Modern technology has now served to confirm and to detail the meticulous clinical and scientific observations made about M.E. before 1988, and the name Myalgic Encephalomyelitis has stood the test of time scientifically for more than 50 years. What we now know about Myalgic Encephalomyelitis includes that;

M.E. is a systemic acutely acquired illness initiated by a virus infection which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name Myalgic Encephalomyelitis.) The CNS is diffusely (and measurably) injured at several levels, these include the cortex, the limbic system, the basal ganglia, the hypothalamus and areas of the spinal cord and its appendages. This persisting multilevel central nervous system (CNS) dysfunction is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process. Myalgic Encephalomyelitis causes a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits.

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus M.E. symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. M.E. affects the body systemically. Even minor levels of physical and cognitive activity, sensory input and orthostatic stress beyond a M.E. patient's individual post-illness limits causes a worsening of the severity of the illness (and of symptoms) which can persist for days, weeks or months or longer. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (eg. to the heart), disease progression and/or death in M.E.

M.E. is a distinct, recognisable disease entity that is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease (within just a few weeks) – providing that the physician has some experience with the illness. Although there is as yet no single test which can be used to diagnose M.E. there are a *series* of tests which can confirm a suspected M.E. diagnosis. Virtually every M.E. patient will also have various abnormalities visible on physical exam. If all tests are normal, if specific abnormalities are not seen on certain of these tests (eg. brain scans), then a diagnosis of M.E. cannot be correct. M.E. is similar in a number of significant ways to multiple sclerosis, Lupus and poliomyelitis (polio). There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus (Bassett 2009, [Online]).

This is not simply theory, but is based upon an enormous body of mutually supportive clinical information which has been published in prestigious peer-reviewed journals all over the world and spans over 70 years. Confirmation of this hypothesis is now supported by electrical tests of muscle and of brain function (CT, MRI, SPECT and PET scans) and by biochemical and hormonal assays, and so on (Chabursky et al. 1992 p. 20) (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 pp. x-xxi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92).

But despite the long history of M.E., and the overwhelming irrefutable evidence that M.E. a distinct organic neurological disease, the perception and treatment of M.E. by the public, the medical profession, the government and the media has changed profoundly since 1988.

- Despite the fact that there are more than 64 different symptoms authentically documented in M.E., and that M.E. has a long history including evidence of virally induced damage to the brain and of outbreaks (and much more) the term M.E. is often used interchangeably with the terms 'fatigue' and 'chronic fatigue' – as if the distinct neurological illness M.E. and the symptom of fatigue were exactly the same.
- The outbreaks of M.E. are virtually never mentioned, nor the long history of M.E.
- The WHO classification of M.E. remains unchanged but is ignored by most doctors and governments.
- Despite the abundance of evidence spanning many decades which disproves the theory, it is now often claimed that some level of psychiatric causation of M.E. has been scientifically proven, even though the relevant studies were conducted not on people with M.E., but instead on non-M.E. patients selected based on the presence of 'fatigue.'

- People with M.E. are often denied basic welfare entitlements, and many do not have access to basic medical care. It is also very common for people with M.E. to be mistreated as psychiatric patients, to be sectioned against their will, forced to participate in graded exercise programs (which are at best useless and at worst cause severe or permanent relapse or even death) or in cognitive behavioural therapy (which is also at best useless and at worst extremely harmful). Many people with M.E. are simply left at home to die alone.
- It is common to read written material on M.E. in the media and produced by government etc. which does not include even one legitimate fact about the illness and is made up entirely of myths and propaganda.

The symptom of 'chronic fatigue' and the distinct neurological illness M.E. each have a different; cause, symptoms, aetiology, pathology, response to treatment, long and short term prognosis – and World Health Organization classification. People with the symptom of chronic fatigue and those with authentic neurological Myalgic Encephalomyelitis share few if any similarities. The suggestion that these two patient groups could somehow represent the exact same patient group and be able to be studied interchangeably is clearly absurd, yet somehow this view has gained widespread acceptance by the media, the public and the medical community and is also reflected in government policy.

So how did this happen?

The creation of many different definitions of 'Chronic Fatigue Syndrome' is how a particular group of psychiatrists (and others with similar vested interests) have superficially 'bridged the gap' as it were between these unrelated patient groups so that they can fraudulently be discussed – to those who are not aware of the subterfuge involved – as if they were one and the same.

What is Chronic Fatigue Syndrome? How is it defined?

The new name CFS and the CFS case definition was created by the CDC in the US in 1988 by a board of eighteen members (many of them psychiatrists); few of which had studied either an epidemic of M.E., or any patients with the illness. This new criteria failed to select patients using any past or current relevant research or lab work, excluded the cardinal symptoms and signs of M.E. and instead focused almost entirely on 'fatigued persons.' CFS was created in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not exist. The three more experienced members of the board refused to sign the final document and withdrew themselves from the (CDC) definitional committee because the proposed new name and definition for the illness were just too different from the M.E. with which they were so familiar (Hooper et al. 2001 [Online]).

In the two most commonly used definitions of CFS – the US 1994 Fukuda (or CDC) definition and the 1991 UK Oxford definition – the only essential symptom required for the diagnosis of CFS to be made is 'chronic fatigue.' All either of these definitions 'define' is a heterogeneous population of sufferers from misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but 'fatigue' (Hooper 2003a. [Online]).

Despite the fact that it was an outbreak of M.E. which these CFS definitions were created to define the vast majority (an estimated 95% *at least*) of the research and articles available today which use the term CFS are not in any way concerned with, or relevant to, Myalgic Encephalomyelitis patients – yet these 'CFS' studies are what is used to determine the treatments that people with M.E. are recommended, or forced, to participate in. The small amount of research done under the name CFS which does relate to M.E. is also virtually always tainted by CFS propaganda. The creation of 'CFS' is an abuse of basic science. Despite the high level of disability and the vast number of patients involved, governments around the world are currently spending \$0 a year on M.E. research.

So why were the renaming and redefining of the distinct neurological disease Myalgic Encephalomyelitis allowed – indeed intended – to become so muddled? Indeed why did Myalgic Encephalomyelitis suddenly need to be renamed or redefined at all? Money. There was an enormous rise in the reported incidence of Myalgic Encephalomyelitis in the late 1970s and 1980s, alarming medical insurance companies in the US. So it was at this time that certain psychiatrists and others involved in the medical insurance industry (on both sides of the Atlantic) began their campaign to reclassify the severely incapacitating and discrete neurological disorder known as Myalgic Encephalomyelitis as a psychological or 'personality' disorder, in order to side-step the financial responsibility of so many new claims (Marshall & Williams 2005a, [Online]). As Professor Malcolm Hooper explains:

In the 1980s in the US (where there is no NHS and most of the costs of health care are borne by insurance companies), the incidence of ME escalated rapidly, so a political decision was taken to rename M.E. as "chronic fatigue syndrome", the cardinal feature of which was to be chronic or on going "fatigue", a symptom so universal that any insurance claim based on "tiredness" could be expediently denied. The new case definition bore little relation to M.E.: objections were raised by experienced international clinicians and medical scientists, but all objections were ignored... To the serious disadvantage of patients, these psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to government, resulting in the withdrawal and erosion of both social and financial support (2003a, [Online]) (2001, [Online]).

This is the reason why the charade that M.E. could be a psychiatric or behavioural disorder or even a 'aberrant belief system' involving mere 'fatigue' exists; not because there is good scientific evidence – or *any* evidence – for the theory, or because the evidence proving organic causes and effects is lacking; but purely because such a view is so **financially and politically convenient and profitable** on such a large scale to a number of extremely powerful corporations and government departments (Hooper et al 2001, [Online]).

So what does a diagnosis of CFS actually mean?

There are now more than nine different definitions of 'CFS.' All each of these flawed CFS definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue.

The fact that a person qualifies for a diagnosis of CFS, based on any of the CFS definitions (a) does not mean that the patient has Myalgic Encephalomyelitis, and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' A diagnosis of CFS – based on any of the CFS definitions – can only ever be a *misdiagnosis*. All a diagnosis of 'CFS' actually means is that the patient has a gradual onset fatigue syndrome which is usually due to a *missed major disease*. As Dr Byron Hyde explains, the patient has:

- a. Missed cardiac disease, b. Missed malignancy, c. Missed vascular disease, d. Missed brain lesion either of a vascular or space occupying lesion, e. Missed test positive rheumatologic disease, f. Missed test negative rheumatologic disease, g. Missed endocrine disease, h. Missed physiological disease, i. Missed genetic disease, j. Missed chronic infectious disease, k. Missed pharmacological or immunization induced disease, l. Missed social disease, m. Missed drug use disease or habituation, n. Missed dietary dysfunction diseases, o. Missed psychiatric disease (2006, [Online]).

Under the cover of 'CFS' certain vested interest groups have assiduously attempted to obliterate recorded medical history of M.E. But M.E. and 'CFS' are NOT the same. As M.E. expert Dr Byron Hyde explains:

Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis. It is not. The CDC 1988 definition of CFS describes a non-existing chimera based upon inexperienced individuals who lack any historical knowledge of this disease process. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance. Any disease process that has major criteria, of excluding all other disease processes, is simply not a disease at all; it doesn't exist. The CFS definitions were written in such a manner that CFS becomes like a desert mirage: The closer you approach, the faster it disappears and the more problematic it becomes.

Patient, physician, and insurer alike have tended to treat this syndrome as a specific disease or illness, with at times a potentially specific treatment and a specific outcome. This has resulted in much confusion. The physician and patient alike should remember that CFS is *not* a disease. It is a chronic fatigue state.

Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would have told the students to search for an occult malignancy, cardiac or other organ disease, or chronic infection. The concept that there is an entity called chronic fatigue syndrome has totally altered that essential medical guideline. Patients are now being diagnosed with CFS as though it were a disease. It is not. It is a patchwork of symptoms that could mean anything (2003, [Online]) (2006, [Online]).

The bogus disease category of 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various psychiatric fatigue states and unrelated fatigue syndromes and other fatiguing illnesses. But people with M.E. are not the only patient group to be negatively affected by this politically-modified science. It is common for patients with a variety of different illnesses with fatigue as a symptom to be misdiagnosed as having 'CFS.' Arbitrarily lumping these disparate patient groups together only hinders each of the patient groups involved in their battle to regain their health.

There are also a variety of negative impacts on doctors and the public (and others) caused by the 'CFS' insurance scam. The only groups which gain from this 'CFS' confusion are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.

Is renaming, refining or sub-grouping 'CFS' the way forward?

Sub-grouping 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. as some groups are suggesting would achieve nothing and only create yet more confusion – which the vested interest groups involved would continue to take advantage of, to the detriment of patients.

The problem is not that 'CFS' patients are being mistreated as psychiatric patients – for a start, some of those patients misdiagnosed with CFS actually *do* have psychological illnesses. CFS is made up of people with depression (and various other psychological illnesses), multiple sclerosis, athletes over-training syndrome,

Fibromyalgia, various self limiting post-viral fatigue syndromes (caused by glandular fever/mono, hepatitis and so on), candida, chronic Lyme disease, burnout, cancer and many more entirely unrelated and already very well-defined conditions. To say that all of these very different conditions – including M.E. – are each subgroups of 'CFS' is just absurd. *There is no such distinct disease as 'CFS'* – that is the entire issue, and the vast majority of patients misdiagnosed with CFS (an estimated 75% at least) **DO NOT** have M.E. and so have no more right to that term (or a variation of it) than to 'cancer' 'diabetes' or 'multiple sclerosis.'

If 'CFS' had instead been given a neutral name, say 'Reeves' syndrome' or 'Holmes' syndrome,' the problems would still be *exactly the same*. Vested interest groups – helped in this task **IMMEASURABLY** by the creation of the bogus disease category of 'CFS' – would still be flooding the medical, political and media communities with lies and propaganda which could only have the end result of making patients seem utterly pathetic and undeserving of any respect or sympathy.

What else could anyone think of patients who supposedly have an illness that is mild and short lived, but which some patients pretend is severely disabling because they 'enjoy the sick role'? What else could anyone think about an illness that cannot in any way be proved despite vast sums being spent on tests and must be taken completely on faith. What else could you/anyone think about an illness that has been proven to be psychological or behavioural but where patients would prefer to actually stay ill rather than to admit that they are mentally ill?

Every media article and government press release about 'CFS' is filled with fictional statements which make it very clear in many different ways that the illness has no scientific validity, and that the patients do not deserve the same respect as other patient groups, but should be treated with contempt. Patients are not merely wrongly categorized as psychologically ill; it is so much more than that. It is persecution; patients are talked about (and lied about) as if they were malingerers and deviants, as if they were beneath contempt and not worthy of even basic respect or medical care, or even any level of kindness or compassion – even from their own friends and family. Whatever 'CFS' had been called, these problems would be **EXACTLY THE SAME**.

The cause of our problems is *not* the mere name 'CFS.' The real issues are:

- The many **DEFINITIONS** of CFS, which define exactly nothing, and allow any number of very different patient groups to be unscientifically treated as if they were one and the same because of the flawed CFS disease construct.
- The involvement of financial and political vested interest groups in what should be a scientific discussion.
- The inappropriate involvement of psychiatrists in treating many different non-psychiatric/psychological illnesses.
- That all of the existing science is being purposefully ignored by those in positions of power
- That most of the 'science' on CFS being produced is seriously flawed and biased, and that often the vested interest groups involved have determined the outcomes of this 'research' before the actual studies have been conducted etc.
- That the media is colluding with the government and other vested interest groups in keeping the public ignorant of the facts surrounding M.E. and the difference between M.E. and 'CFS.'
- That there is no such disease/s as 'CFS' and so every diagnosis of CFS is a *misdiagnosis*.

Millions of patients are being denied their basic rights to a correct diagnosis and treatment for their illness and their best chance to regain their health. These patients are also subject to appalling levels of abuse, neglect and mistreatment, even unto death in some cases, merely for financial gain.

The infectious disease known since 1956 as Myalgic Encephalomyelitis already has a historically and medically correct name and definition and WHO classification. We also have clear definitions and names for Fibromyalgia, post-viral fatigue syndromes, PTSD, burnout, Lyme disease, Candida, Adrenal exhaustion, cancer, depression, athletes over-training syndrome and each of the other illnesses commonly misdiagnosed as 'CFS.'

The only thing that makes any sense is for us to fight together to get rid of 'CFS' in name and definition, and to have patients correctly diagnosed with and treated for with whichever illnesses they actually have, including M.E., in a scientific and ethical manner – without any self-interested interference by financial vested interest groups.

The distinction must be made between terminology and definitions. The terminology is often used interchangeably, incorrectly and confusingly and new ill-defined umbrella terms such as 'ME/CFS' 'ME-CFS' 'CFS/ME' 'CFIDS' and others just increase this confusion. However, the **DEFINITIONS** of M.E. and CFS are very distinct, and it is these *definitions* which are of primary importance. In summary:

1. **Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a

person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.

2. **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely 'fatigued' instead of having M.E. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

Sub-grouping 'CFS' or renaming (as some CFS groups are proposing) would only waste another 20 years or more and ensure that the relentless abuse, mistreatment, neglect and needless deaths continue. This proposal would not further the interests of people, with M.E., nor any of those patients misdiagnosed with CFS. Yet again, only vested interest groups will benefit. Changing the name of the bogus disease construct of 'CFS' to some variation on the term M.E. is not at all a step in the right direction. If successful, this move will actually be a huge step BACKWARD for everyone with M.E. *and* all those patients misdiagnosed with CFS. It will make it harder than ever for anyone to distinguish between 'CFS' and authentic M.E., and for those misdiagnosed with CFS to be able to receive a correct diagnosis and treatment finally. It must not be allowed to succeed. The groups proposing this action do NOT speak for, or represent, the M.E. community.

The 'CFS name change proposal' seems nothing more than a political stunt; designed to appease (justifiably) angry patients and make them feel like something is being done and that progress is being made finally – but not to actually effect any real change. The proposal that the name of 'CFS' should be changed to a variation on the term M.E. – despite the fact that the term is completely scientifically inaccurate for the vast majority of the patients involved and that this term has already been TAKEN by a very well-defined (and scientifically sound) patient group for over 50 years – merely because it 'sounds a lot more serious' makes a mockery of legitimate advocacy, and of science, logic and ethics.

So where do we go from here? How do we stop this abuse of science?

This appalling abuse and neglect of such severely ill people on such an industrial scale is inhuman and has already gone on far too long. The only way forward for M.E. patients and all of the diverse patient groups commonly misdiagnosed with 'CFS' – both of which are denied appropriate support, diagnosis and treatment, and may also be subject to serious medical abuse and inappropriate interventions – is that the bogus disease category of 'CFS' must be abandoned. The only way forward, for the benefit of society and every patient group involved, is that:

1. The fictional disease category of 'CFS' must be abandoned Patients with fatigue (and other symptoms) caused by a variety of different illnesses need to be diagnosed correctly with these illnesses if they are to have any chance of recovery; not given a meaningless Oxford or Fukuda 'CFS' misdiagnosis. (Some of the conditions commonly misdiagnosed as 'CFS' are very well defined and well-known illnesses and very treatable – but ONLY once they have been correctly diagnosed). Patients with M.E. need to be given this same opportunity.

Patients with depression need to be diagnosed with depression and then treated for depression. Patients with cancer should be diagnosed with cancer and then treated as is appropriate for the kind of cancer they have, and so on. Each of the patient groups involved must be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group.

Physicians who diagnose 'CFS' in any patient experiencing new onset fatigue without looking and testing for the true cause of the symptoms do their patients – and themselves – a great disservice. Some of the conditions commonly misdiagnosed as CFS are very well defined and well-known illnesses and very treatable – but only once they have been correctly diagnosed. Some conditions are also very serious or can even be fatal if not correctly diagnosed and managed, including Myalgic Encephalomyelitis. (It is not uncommon for people with cancer – which causes significant fatigue – to be misdiagnosed with CFS and to die needlessly due to a lack of appropriate treatment, for example.)

Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery. This process must begin with a correct diagnosis if at all possible. **A correct diagnosis is half the battle won.** A diagnosis of CFS – based on any of the definitions of CFS – can only ever be a *misdiagnosis*. Doctors must return to the age-old medical principals of correct diagnosis (a) careful history, (b) detailed physical examination and (c) appropriate investigation (Hyde 2006, [Online])

2. The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization (WHO) classification of M.E. as an organic neurological illness must be accepted and adhered to in all official documentations and government policy. There were sound medical reasons for the creation of the name in 1956, and for the classification of the illness by the WHO in 1969; neither of which has changed in the interim. Professor Malcolm Hooper explains:

The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. The currently version ICD-10 lists M.E. under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. (2006, [online])

Despite misleading claims made to the contrary by vested interest groups, there is well-documented evidence of inflammation of the brain and spinal cord in M.E. spanning over 50 years, *but it is true* that there is no evidence of inflammation of the brain or spinal cord in states of 'chronic fatigue' or 'tiredness' and other non-M.E. illnesses which may be commonly misdiagnosed as 'CFS' (Hooper n.d., [Online]) (Hyde 2006, [Online]).

M.E. is a distinct recognisable entity, with several unique features, which can be diagnosed relatively early in the course of the disease providing the physician has some experience with the illness. M.E. can easily be distinguished from various chronic fatigue states, and other unrelated 'fatiguing' illnesses. People with M.E. must be diagnosed with M.E. and treated for M.E., based on research which also involves M.E. patients again, finally. The M.E. community does not need to wait for official 'permission' to renew the name and scientifically and historically correct definition of M.E., these rights exist today (as they have since 1969) under the WHO ICD.

3. People with M.E. must also immediately stop being treated as if they are mentally ill, or suffer with a behavioural illness, or as if their physical symptoms do not exist or can be improved with 'positive thinking' or exercise – or mixed in with various non-M.E. 'fatigue' sufferers in any way. People with M.E. must also be given access to basic medical care, financial support and other appropriate services (including funding for legitimate M.E. research) on an equal level to what is available for those with comparable illnesses (eg. multiple sclerosis or Lupus). The facts about M.E. must again be taught to medical students, and included in mainstream medical journals and already practicing physicians must be brought up to speed about M.E. It must be as unacceptable for physicians to be ignorant about M.E. as multiple sclerosis, diabetes or any other common and serious disease. M.E. expert Dr Elizabeth Dowsett explains that:

M.E. Research workers must be encouraged and appropriately funded to work in this field. However they should first be directed to papers published before 1988, the time at which all specialised experience about poliomyelitis and associated infections seem to have vanished mysteriously! (2001a, [Online])

Myalgic Encephalomyelitis is a distinct infectious neurological disease – not a problem of medically unexplained 'fatigue.' Patients with M.E. must be treated based on the scientific facts, rather than misinformation and falsehoods based on political and financial considerations.

Again, the only groups which gain from the 'CFS' confusion are insurance companies and various other organisations and corporations which have a vested financial and political interest in how these patients are treated, including the government. **For the benefit of all of the patients groups involved, the medical community and society at large, the bogus disease category of CFS must be abandoned.** There is no other logical or ethical solution. The 'CFS' fiction has already ruined (or ended) enough lives.

More information:

- The new paper: Why 'CFS' must be abandoned: Extra features comments from other members of the M.E. community which also explain why renaming, refining or sub-grouping 'CFS' cannot work and why 'CFS' must be abandoned, (and why Myalgic Encephalomyelitis must remain the name used only for Myalgic Encephalomyelitis patients) and so on.
- For more information about M.E. see: What is Myalgic Encephalomyelitis? Extra extended version.
- Those patients (mis)diagnosed with 'CFS' (and who do not have M.E.) are advised to read the following papers: The Misdiagnosis of 'CFS' and Where to after a 'CFS' (mis)diagnosis?. See also: Who benefits from 'CFS' and 'ME/CFS'?, Problems with the so-called "Fair name" campaign: Why it is in the best interests of all

patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename 'CFS' as 'ME/CFS'

- See On the Name Myalgic Encephalomyelitis for more information on the evidence for inflammation of the brain and spinal cord in M.E. and other issues surrounding the name Myalgic Encephalomyelitis.
- For more information on why vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'CFIDS' and 'Myalgic Encephalopathy' and others must also be abandoned see: What is Myalgic Encephalomyelitis? Extra extended version and Who benefits from 'CFS' and 'ME/CFS'?. *None* of these terms should be used interchangeably with Myalgic Encephalomyelitis.
- M.E. is a distinct, recognisable entity that can be diagnosed relatively early in the course of the disease, providing the physician has some experience with the illness. New TESTABLE definitions such as The Nightingale Definition of M.E. now also make diagnosis easier than ever before; even for those with no experience with the illness. See: Testing for M.E. for more information.
- To read a list of all the articles on this site suitable for different groups such as M.E. patients, carers, friends and family, the 'CFS' misdiagnosed, doctors or severe M.E. patients and so on, see the Information Guides page.

Additional notes on this text:

1. What does the term ICD-CFS mean? The various definitions of 'CFS' *do not* define M.E. Myalgic Encephalomyelitis is an organic neurological disorder as defined at G.93.3 in the World Health Organization's International Classification of Diseases (ICD). The definitions of 'CFS' do not reflect this. The 'CFS' definitions are not 'watered down' M.E. definitions, as some claim. They are not definitions of M.E. at all.

However, ever since an outbreak of M.E. in the US was given the label 'CFS,' the name/definition 'CFS' has prevailed for political reasons. 'CFS' is widely though wrongly applied to M.E. as well as to other diseases. The overwhelming majority of 'CFS' research does not involve M.E. patients and is not relevant *in any way* to M.E. patients. However, a very small amount (a minuscule percentage) of research published under the name 'CFS' clearly does involve a significant number of M.E. patients as it details those abnormalities which are unique to M.E. Sometimes the term 'ICD-CFS' is used in those studies and articles which, while they use the term 'CFS,' do relate to some extent to authentic M.E. General problems with the term 'ICD-CFS' include the following:

- 1) The main problem is that the term 'ICD-CFS' implies that 'CFS' has a WHO ICD classification as a neurological disease. 'CFS' has no ICD listing as a neurological disease. Indeed, in the version of the ICD in use in most of the world, 'CFS' has no classification at all. Myalgic Encephalomyelitis was classified as a distinct neurological disease in the WHO ICD in 1969 based on a large body of compelling scientific evidence. To imply that 'CFS' research and the definitions of 'CFS' have been properly evaluated by the WHO and classified as neurological is erroneous. Of course 'CFS' can never be classified as a neurological illness because none of the 'CFS' definitions define a neurological disease, or any distinct disease.
- 2) It is also erroneous to imply that the WHO has deemed 'CFS' to relate to Myalgic Encephalomyelitis in any way. The term ICD-CFS incorrectly suggests that 'CFS' and M.E. are synonymous terms for a single entity.
- 3) The term also implies a lack of scientific rigour in the ICD, suggesting that definitions as vague and as problematic as those of 'CFS' would be accepted by the WHO as the basis for a neurological classification. If this were to be believed, it would weaken the authority of Myalgic Encephalomyelitis's ICD classification.
- 4) In addition to its use in relation to research, some people use the term 'ICD-CFS' to refer to the disease generally. The term is usually used by people who are aware of the psychological paradigm of 'CFS,' and who want to indicate a real, biological disease rather than a psychological one. However, which exact disease or diseases are being referred to with this term varies considerably from one author to another. As with terms such as 'ME/CFS' the term 'ICD-CFS' only increases confusion as it has no agreed definition and many different groups use it to refer to very different, often very mixed, patient groups.

The overwhelming majority of 'CFS' research does not involve M.E. patients and is not relevant *in any way* to M.E. patients. A small number of 'CFS' studies refer in part to people with M.E. but it may not always be clear which parts refer to M.E. Unless studies are based on an exclusively M.E. patient group, results cannot be interpreted and are meaningless for M.E. Thus while it is important to be aware of the small amount of research findings that do hold some value for M.E. patients, using the term 'ICD-CFS' to refer to this research is misleading and in many ways just damaging as using terms and concepts like 'ME/CFS' or 'CFS/ME.'

- For further details of the WHO ICD classifications of M.E. and 'CFS' worldwide (and why terms such as 'ICD-CFS,' 'ME/CFS' and 'Myalgic Encephalopathy' must be avoided) please see the new paper by patient advocate Lesley Ben entitled: The World Health Organization's International Classification of Diseases (WHO ICD), ME, 'CFS,' 'ME/CFS' and 'ICD-CFS'

- For more information about the WHO classifications of M.E. and 'CFS' worldwide please see the articles by patient advocate [LK Woodruff](#).
- Virtually all of the research which does relate to M.E. (at least in part) but which uses the term/concept of 'CFS' (or ME/CFS, or CFIDS etc.) is also contaminated in some way by 'CFS' misinformation. Most often these papers contain a bizarre mix of facts relating to both M.E. and 'CFS.' For more information on some of the most common inaccuracies and 'CFS' propaganda included in this research, see the paper: [Putting Research and Articles on Myalgic Encephalomyelitis into Context](#)

2. *A further note on the current 'CFS' name change proposal:* It is *madness* to suggest that CFS should be renamed as ME-CFS or CFS/ME, as some US CFS groups are currently advocating. It is unethical to use the name of another patient group merely to try to further your own interests, particularly when this would cause significant additional harm and hardship to that group (and when that group is *far* more severely ill, disabled and vulnerable).

It may well be the case that patients with various post-viral fatigue syndromes (caused by glandular fever or mononucleosis, hepatitis, Ross River virus etc.), some of the main groups pushing for this absurd renaming, would benefit from these conditions being renamed in some way, but this new name must be one which is not TAKEN already by an entirely unrelated and already well-defined patient group! (The fact that some of these patients, and others, may fit the Canadian criteria for 'ME/CFS' does not mean that these patients can be correctly diagnosed with M.E. – as per Ramsay/Richardson/Dowsett and Hyde – nor that these illnesses are the same or 'virtually the same' as M.E. They are not. The Canadian 'ME/CFS' guidelines are not a pure/accurate M.E. definition. Read more about the benefits and the limitations of the Canadian Guidelines at: [Testing for M.E.](#)). If the name change travesty is successful however, it would at least be preferable if the term Myalgic Encephalomyelitis were not used and that the far less specific (and non-synonymous term) 'Myalgic Encephalopathy' was used in its stead; leaving at least some distinction between genuine neurological M.E. and the vast array of illnesses misdiagnosed as 'CFS.'

M.E. expert [Dr Byron Hyde](#) explains that: 'Some individuals, dissatisfied with the name chronic fatigue syndrome, [have] suggested changing it to myalgic encephalomyelitis or some variation of that name. This would be unwise. M.E. and CFS should be separated as definitions. They are not the same' (2003, [Online]).

The M.E. and CFS communities must reject this ridiculous proposal, and not let these groups treat us like the idiots they think we are. We must also look very carefully at the motivations of those who created something so counter to the best interests of both M.E. patients and those misdiagnosed with CFS, and whether or not continuing to support such groups and individuals is in our best interests. For more information please read: [Who benefits from 'CFS' and 'ME/CFS'?, Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename 'CFS' as 'ME/CFS' and Problems with the use of 'ME/CFS' by M.E. advocates,](#)

References

All of the information concerning Myalgic Encephalomyelitis on this website is fully referenced and has been compiled using the highest quality resources available, produced by the world's leading M.E. experts.

More experienced and more knowledgeable M.E. experts than these – [Dr Byron Hyde](#) and [Dr. Elizabeth Dowsett](#) in particular – do not exist. Between Dr Byron Hyde and Dr. Elizabeth Dowsett, and their mentors the late Dr John Richardson and Dr Melvin Ramsay (respectively), these four doctors have been involved with M.E. research and M.E. patients for well over 100 years collectively, from the 1950s to the present day. Between them they have examined more than 15 000 individual (sporadic and epidemic) M.E. patients, as well as each authoring numerous studies and articles on M.E., and books (or chapters in books) on M.E. Again, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

This paper is merely intended to provide a brief summary of some of the most important facts of M.E. It has been created for the benefit of those people without the time, inclination or ability to read each of these far more detailed and lengthy references created by the world's leading M.E. experts. The original documents used to create this paper are essential additional reading however for any physician (or anyone else) with a real interest in Myalgic Encephalomyelitis. [Click here](#) to view the reference list for this paper. For more information see the [References](#) page.

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The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

A one-page summary of the facts of M.E.

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Taken from www.hfme.org



- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease with the ICD code G.93.3.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.
- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart. However, the hearts of M.E. patients only pump barely enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input. This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death. If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive. *M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*
- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: What is M.E.? Extra extended version. Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.