

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.

M.E. research in context - Summary

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Just like any other field where many billions of dollars are at stake, the areas of science, medicine and healthcare are as open as any other to clever manipulation by those with something to gain either financially or politically by skewing and misrepresenting the facts. Research into Myalgic Encephalomyelitis (M.E.) is a prime example of this. It is because of the enormous amounts of money at stake that the charade that M.E. could be a psychiatric or behavioural disorder or even a 'belief system' continues; not because there is good scientific evidence (or indeed any evidence) for it, or because the evidence proving organic causes and effects is lacking – but because such a view is so *financially and politically convenient and profitable* on such a large scale to a number of powerful corporations and Government departments. (See: [Who benefits from 'CFS' and 'ME/CFS'?](#))

Scientifically however, these theories and ideas have been utterly discredited and disproven decades ago, decades *before* the 'CFS' propaganda was created (and literally more than a THOUSAND times over since then) and are no more scientifically viable than are those of a 'flat Earth.'

The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct, and it is the definitions of each of these terms which is of primary importance. *The distinction must be made between terminology and definitions.* In short:

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.

What follows are explanations of the scientific reality behind some of the most commonly used myths and propaganda concerning M.E.:

"...the primary symptom is severe fatigue..."

The defining feature of M.E. is not fatigue or tiredness. M.E. is characterised primarily by damage to the central nervous system (the brain) which results in dysfunctions and damage to many of the body's vital systems and a loss of normal internal homeostasis. The 'f' word was selected in 1988 entirely for what it could achieve politically: it was never intended to be a genuine medical description of the symptomatology of this illness. Fatigue is a symptom of many different illnesses as well as a feature of normal everyday life – but it is not a defining nor even an essential symptom of M.E. Understanding of this illness would be greatly advanced if the misleading and confusing practice of using such inaccurate terms such as fatigue (or tiredness/low energy) were to be immediately stopped by legitimate M.E. researchers/advocates.

".....symptoms are vague, there are no physical signs and so diagnosis is very difficult..."

There are in fact a variety of physical signs in M.E. patients as well as a series of tests which can be done to confirm a suspected M.E. diagnosis and symptoms may indeed be clearly articulated. If a physician has some experience with the illness, M.E. is not a difficult illness to diagnose (and may be diagnosed very early in the disease) and non fatigue-based definitions such as the Nightingale definition of M.E. now make diagnosis easier than ever before; even for those with no experience with the illness. Whilst various ‘fatiguing conditions’ with a variety of different aetiologies may be made up of vague and mild ‘everyday’ type symptoms, have no physical signs and no tests which can aid diagnosis, M.E. is a distinct neurological illness with a distinct list of symptoms, physical signs and diagnostic (and other) tests. It bears no relationship with such unrelated ‘fatiguing conditions.’

"...it is an illness which can only be diagnosed by exclusion....there are no lab tests which have shown abnormalities in these patients..."

The fact that there is as yet no *single* test which can diagnose the illness is often written in a way which implies that there are NO lab tests anywhere which have ever shown anything at all being organically abnormal in any M.E. patients. This is simply an absurd claim. While there is no SINGLE test which can confirm a suspected M.E. diagnosis, there are a SERIES of tests which can. Furthermore, *hundreds* of different studies have found measurable and in some cases extremely severe abnormalities in many different bodily systems of M.E. patients. M.E. is a distinct illness which can be easily diagnosed by careful analysis of a patient's symptomatology, looking for some of the physical signs of M.E. and also performing a series of specific tests (including MRI and SPECT brain scans). Tests will only all be normal in M.E. – as with all illnesses – if completely the wrong tests are done.

"...despite the illness receiving extensive funding for research....."

Statements which imply that there has been extensive genuine research into the biomedical facts of the illness yet that there have been only scant results to be found are utterly divorced from reality. The exact opposite is true. Indeed it is miraculous that so much good research has turned up given the meagre funding and many other drawbacks, which speaks to the seriousness of the disease. Governments worldwide currently spend 0\$ a year on M.E. research.

"...it is a mysterious, baffling, medically unexplained illness..." "the illness transcends the boundaries between the mind and the body like no other..."

The ‘bio psychosocial’ approach is just a new way of pushing the same old fatally flawed psychiatric theories yet again. M.E. is no more a bio psychosocial illness than Multiple Sclerosis, Parkinsons or any other organic neurological disease. M.E. is also no more ‘mysterious,’ ‘baffling’ or ‘medically unexplained’ than either of these illnesses. Many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research. These are well-documented, scientifically sound explanations for why patients are often bedridden and unable to maintain an upright posture.

"...of course every patient's anxiety and depression must be treated first..."

It is often assumed that 100% of all patients with M.E. suffer with significant levels of anxiety and depression. In fact, studies have shown the depression rates in M.E. patients to be similar to those of Multiple Sclerosis or Rheumatoid Arthritis patients. The figure is in reality nowhere near even 50%, let alone 100%. Many researchers compound this error by also writing as if psychiatric or ‘behavioural’ causation of the illness has also been legitimately proven. The key word here is ‘legitimately.’ Therapies based upon these flawed theories are also often written about as if they have been legitimately proven to be effective (CBT and GET for example). The key word here is again, ‘legitimately.’ *Studies done using ‘fatigued’ patients have no relevance whatsoever to genuine neurological M.E. patient groups.*

"...these CFS patients showed..."

None of the CFS definitions defines or describes M.E. nor any other distinct illness named ‘CFS.’ All each of these flawed definitions ‘define’ is a heterogeneous population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states with little in common but the symptom of fatigue. M.E. and ‘CFS’ are not the same. Every diagnosis of ‘CFS’ is a misdiagnosis.

"...only mild abnormalities were found. Nowhere near severe enough to account for patients reports of..."

Patients being studied are almost exclusively those in the mild – to *possibly moderate* in some cases – range of M.E. severity. A recent study showed that more than 99% of all studies on M.E. involved such patients. The ‘mild’ abnormalities shown in some studies may mean that whatever is being tested for is not relevant to the pathology of M.E., but they may also merely be indicative of the fact that mildly ill patients will often show only mild abnormalities. This must always be kept in mind when reading research.

".....is common in CFS. These chronic fatigue patients also..."

The word 'syndrome' completely changes the meaning of the words preceding it. People with chronic fatigue may be tired because of cancer, Multiple Sclerosis, vitamin deficiency, a sleep disorder, depression or a large number of other causes. Up to 20% of the population may have some form of chronic fatigue. 'CFS' is not the same thing as 'chronic fatigue' and neither of these terms is synonymous with Myalgic Encephalomyelitis. When these 3 terms are used interchangeably **it makes what is being written utterly nonsensical.**

"...cancer patients also experience severe fatigue, so...."

Many studies which misrepresent the main feature of the illness as 'fatigue' then go on to compound this error by comparing and discussing the legitimate fatigue experienced by patients with many other illnesses as if this had relevance. As the word fatigue is being misused in being applied to M.E. patients, studies on the level of fatigue in other illnesses and how this can be improved have absolutely no relevance to defining the symptomatology or pathology of M.E., and vice versa.

OMISSIONS:

Sometimes it is what studies and other writings on M.E. *don't* say that is every bit as misleading as the false and misleading statements which are used. These include:

1. The deaths from M.E. are almost always omitted, as is the true (and brutal) severity of the illness and the true rates of recovery (which are unfortunately nowhere near the 100% often claimed, or even 10%).
2. The more than 60 outbreaks of M.E. recorded worldwide are almost always omitted.
3. The long history of M.E. research is often omitted (the illness did *not* just suddenly appear in the 1980s for the first time).
4. The enormous amount of solid and credible research irrefutably proving organic and severe illness in M.E. patients (some of it in existence from as far back as the 1930s and 1950s) is often omitted completely.
5. The real constellation of symptoms is also rarely mentioned with many articles listing only some of the very minor and *optional* symptoms (eg. fatigue, sore throat, joint aches) as if these are what characterise the illness, while omitting much or even all of the true symptomatology.

- For further information see the full-length [Putting research and articles on M.E. into context](#)
- For more information on all aspects of M.E. see 'What is M.E.? See the [Research & Articles](#) section to start reading through some of the best research and articles on M.E. available.
- For more information on the financial and political issues surrounding the creation of the bogus disease category 'CFS' and why M.E. is not the same thing as 'CFS' see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Smoke and Mirrors](#), [What is M.E.?](#), [The misdiagnosis of CFS](#) and [Why the disease category of 'CFS' must be abandoned.](#)

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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 purely 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. See the full-length text or the [References](#) page.

“People in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of the persecuted, when they too come up against a wall of utter indifference.” Professor Hooper 2003

‘Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. 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’ Dr Byron Hyde M.D. 2006

The vested interests of the Insurance companies and their advisers must be totally removed from all aspects of benefit assessments. There must be a proper recognition that these subverted processes have worked greatly to the disadvantage of people suffering from a major organic illness that requires essential support of which the easiest to provide is financial. The poverty and isolation to which many people have been reduced by ME is a scandal and obscenity. Professor Malcolm Hooper 2006

To the very few physicians still practicing today who began seeing patients with this illness some 40 years ago and who have continued to record and publish their clinical findings throughout, the current enthusiasm for renaming and reassigning this serious disability to subgroups of putative and vague "fatigue" entities, must appear more of a marketing exercise than a rational basis for essential international research. It was not always so unnecessarily complicated! Dr Elizabeth Dowsett

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. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. Professor Malcolm Hooper 2006

M.E. is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction which causes a breakdown in bodily homeostasis (The brain can no longer receive, store or act upon information which enables it to control vital body functions, cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance, appreciation of space, shape etc). It has an UNIQUE Neuro-hormonal profile. .Dr Elizabeth Dowsett

M.E. appears to be in this same family of diseases as paralytic polio and MS. M.E. is less fulminant than MS but more generalized. M.E. is less fulminant but more generalized than poliomyelitis. This relationship of M.E.-like illness to poliomyelitis is not new and is of course the reason that Alexander Gilliam, in his analysis of the Los Angeles County General Hospital M.E. epidemic in 1934, called M.E. atypical poliomyelitis. Dr Byron Hyde 2006

‘Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would 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’ Dr Byron Hyde 2003

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myalgic

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

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- 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.