

What is M.E.? A historical, medical and political overview

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Myalgic Encephalomyelitis (M.E.) is a debilitating acquired neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder.

M.E. can occur in both epidemic and sporadic forms, and over 60 outbreaks of M.E. have been recorded worldwide since 1934. M.E. is similar in a number of significant ways to Multiple Sclerosis, Lupus and poliomyelitis (polio).

M.E. can be extremely severe and disabling and in some cases the disease is fatal.

Is M.E. a new illness? What does the name Myalgic Encephalomyelitis mean?

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

The Wallis description of M.E. was created in 1957, and in 1959 Sir Donald Acheson (a former UK Chief Medical Officer) conducted a major review of M.E.

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.

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]).

Since 1956 the term Myalgic Encephalomyelitis has been used to describe the illness in the UK, Europe Canada and Australasia. This term has stood the test of time for more than 50 years. The recorded medical history of M.E. as a debilitating organic neurological illness affecting children and adults is substantial; it spans over 80 years and has been published in prestigious peer-reviewed journals all over the world (Hyde 1998, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001b, [Online]).

As award winning microbiologist and M.E. expert [Dr Elizabeth Dowsett](#) explains: ‘There is ample evidence that M.E. is primarily a neurological illness, although non-neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised’ (n.d.b, [Online]).

M.E. is not defined by mere ‘fatigue’

M.E. is not synonymous with being tired all the time. If a person is very fatigued for an extended period of time this does not mean they are having a ‘bout’ of M.E. Such a suggestion is no less absurd than to say that prolonged fatigue means a person is having a ‘bout’ of Multiple Sclerosis, Parkinson’s disease or Lupus. If a person is constantly fatigued this should not be taken to mean that they have M.E., no matter how severe or prolonged their fatigue is.

Fatigue is a symptom of many different illnesses as well as a feature of normal everyday life – but it is not a defining symptom of M.E., or even an essential symptom of M.E.

The terms ‘fatigue’ and ‘chronic fatigue’ were not associated with defining this illness until the entity of ‘Chronic Fatigue Syndrome’ was created in 1988 in the USA (Hyde 2006, [online]). But M.E. and ‘CFS’ are *not* synonymous terms.

‘Fatigue’ and ‘feeling tired all the time’ are not at all the same thing as the very specific type of *paralytic muscle weakness* or *muscle fatigue* which is characteristic of M.E. (caused by mitochondrial dysfunction) and which affects every organ and cell in the body, including the brain and the heart. This causes – or significantly contributes to – such problems in M.E. as cardiac insufficiency (a type of heart failure), orthostatic intolerance or POTS (inability to maintain an upright posture), blackouts, reduced circulating blood volume (and pooling of the blood in the extremities), seizures (and other neurological phenomena), memory loss, problems chewing/swallowing, episodes of partial or total paralysis, muscle spasms/twitching, extreme pain, problems with digestion, vision disturbances, and breathing difficulties.

These problems are exacerbated by even trivial levels of physical and cognitive activity, sensory input and orthostatic stress beyond a patient’s individual limits. People with M.E. are made very ill and disabled by this problem with their cells; it affects virtually every bodily system and has also lead to death in some cases. Many patients are housebound and bedbound and are often so ill that they feel they are about to die. People with M.E. would give *anything* to only be severely ‘fatigued’ or ‘tired all the time’ (Bassett 2010, [Online]).

Fatigue, post-exertional fatigue or malaise may occur in many different illnesses such as various post-viral fatigue states or syndromes, Fibromyalgia, Lyme disease, and many others, but what is happening with M.E. patients is an entirely different and unique problem of a much greater magnitude. These terms are not accurate or specific enough to describe what is happening in M.E.

M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of ‘chronic fatigue’ (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d., [Online]).

- For more information see [M.E. is not fatigue, or 'CFS'](#). Many of the world’s leading M.E. experts have spoken out strongly against claims that ‘fatigue’ is the defining/essential symptom of M.E. See [M.E. is not defined by 'fatigue'](#) to read some of their comments.
- For more information on the symptoms of M.E., including the unique reaction people with M.E. have to activity, see: [The ultra-comprehensive M.E. symptom list](#).

If M.E. and ‘CFS’ are not synonymous terms, why do some groups claim that they are? What is ‘CFS’?

The disease category of ‘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.

Why was the renaming and redefining of the distinct neurological disease M.E. allowed to become so muddled? Indeed, why did Myalgic Encephalomyelitis suddenly need to be renamed or redefined at all?

The answer is **Money**. There was an enormous rise in the reported incidence of M.E. 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 M.E. 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 M.E. 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 ongoing "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 Ministers and to Members of Parliament, resulting in the withdrawal and erosion of both social and financial support [for M.E. patients]. Influenced by these psychiatrists, government bodies around the world have continued to propagate the same falsehoods with the result that patients are left without any hope of understanding or of health service provision or delivery. As a consequence, government funding into the biomedical aspects of the disorder is non-existent. (2003a, [Online]) (2001, [Online])

The psychiatrist Simon Wessely – arguably the most powerful and prolific author of papers which claim that M.E. is merely a psychological problem of 'fatigue' – began his rise to prominence in the UK at the same time the first CFS definition was being created in the USA (1988). Wessely, and his like-minded colleagues – a small group made up mostly but not exclusively of psychiatrists (colloquially known as the 'Wessely School') has gained dominance in the field of M.E. in the UK (and increasingly around the world) by producing vast numbers of papers which purport to be about M.E.

Wessely claims to specialise in M.E. but uses the term interchangeably with chronic fatigue, fatigue or tiredness, plus terms such as neurasthenia, CFS and 'CFS/ME' (a confusing and misleading term he created himself). He claims that psychiatric states of ongoing fatigue and the distinct neurological disorder M.E. are synonymous. Despite all the existing contradictory evidence, Wessely (and members of the Wessely School) assert that M.E. is a behavioural disorder, with no physical signs of illness or abnormalities on testing, that is perpetuated by 'aberrant illness beliefs' 'the misattribution of normal bodily sensations,' and that patients 'seek and obtain secondary gain by adopting the sick role' (Hooper & Marshall 2005a, [Online]).

The Wessely School and collaborators have assiduously attempted to obliterate recorded medical history of M.E. even though the existing evidence and studies were published in prestigious peer-reviewed journals and span over 70 years. Wessely's claims, and those of his colleagues around the world, have flooded the worldwide literature to the extent that medical journals rarely contain any factual and unbiased information about M.E. most clinicians are effectively being deprived of the opportunity to obtain even the most basic facts about the illness.

For at least a decade, serious questions have been raised in international medical journals about possible scientific misconduct and flawed methodology in the work of Wessely and his colleagues. It is only relatively recently however that his long-term involvement as medical adviser – and board member – to a number of commercial bodies with a vested interest in how M.E. is managed have been exposed.

This is the sole reason the myth that M.E. is a psychiatric or behavioural 'fatiguing' disorder or even an 'aberrant belief system' continues: not because there is good scientific evidence for the theory, or because the evidence proving organic causes and effects is lacking, but because such a theory is so **financially and politically convenient and profitable** on such a large scale to a number of extremely powerful corporations (Hooper et al 2001, [Online]).

As Dr Elizabeth Dowsett observes, these financially motivated theories bear as much relation to legitimate science as Astrology does to Astronomy (1999b [Online]).

Professor Malcolm Hooper goes on to explain:

Increasingly, it is now "policy-makers" and Government advisers, not experienced clinicians, who determine how a disorder is classified and managed in the NHS: the determination of an illness classification and the provision of policy-driven "management" is a very profitable business. To the detriment of the sick, the deciding factor governing policies on medical research and on the management and treatment of patients is increasingly determined not by medical need but by economic considerations. There is a gross mismatch between the severity and complexity of M.E. and the medical and public perception of the disorder (2003a, [Online]).

Members of the 'Wessely school' in the UK including Wessely, Sharpe, Cleare and White, their US counterparts Reeves, Straus etc of the CDC, in Australia Lloyd, Hickie etc and the clinicians of the Nijmegen group in the Netherlands each support a bogus psychiatric or behavioural paradigm of 'CFS' and recommend rehabilitation-based approaches such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as the most useful interventions for 'CFS' patients.

It is important to be aware that none of these groups is studying patients with M.E. Each of these groups uses a definition of 'CFS,' or has created their own, which does not select those with M.E. but instead selects those with various types of psychiatric and non-psychiatric fatigue. These inappropriate interventions are at best useless and at worst extremely harmful or fatal for M.E. patients.

The creation of the bogus disease category 'CFS' has been used to impose a false psychiatric paradigm of M.E. by allying it with various unrelated psychiatric fatigue states and post-viral fatigue syndromes for the benefit of various (proven) financial and political interests. The resulting 'confusion' between the distinct neurological disease M.E. and the bogus disease category of 'CFS' has caused an overwhelming additional burden of suffering for those who suffer from M.E. and their families.

It's a huge mess, that is for certain - but it is not an *accidental* mess - that is for certain too (Hyde 2006a, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]).

- To read about the vast difference between M.E. and 'CFS' (and how such a small (but powerful) group of vested interest psychiatrists have come to influence the opinions of the worldwide medical community about M.E.) see: [Who benefits from 'CFS' and 'ME/CFS'?](#) and [Smoke and mirrors](#) on HFME and also [A Brief History of Myalgic Encephalomyelitis & An Irreverent History of CFS](#) by Dr Byron Hyde
- For information on how the 'CFS' scam affects all parts of an M.E. patient's life, see [M.E.: The shocking disease](#)

What does a diagnosis of 'CFS' actually mean?

There are now more than nine different definitions of 'CFS.' each of these flawed 'CFS' definitions 'define' a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and 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 M.E., 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:

- 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., even though the existing evidence has been published in prestigious peer-reviewed journals around the world and spans over 70 years.

[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 (2006, [Online]).

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) is that the bogus disease category of 'CFS' must be abandoned.

Every patient deserves the best possible opportunity for appropriate treatment for their illness and for recovery and this process must begin with a correct diagnosis if at all possible. *A correct diagnosis is half the battle won* (Hyde 2006a, 2006b, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett n.d., [Online]).

- For more information on why the bogus disease category of 'CFS' must be abandoned see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [The misdiagnosis of 'CFS'](#), [Why the disease category of 'CFS' must be abandoned](#) and [Smoke and Mirrors](#).
- Those patients misdiagnosed 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?](#)
- *An additional note on 'fatigue'*: Just as some M.E. sufferers will experience other non-essential symptoms such as vomiting or night sweats some of the time, but others will not, the same is true of fatigue. The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms – the presence or absence of mere 'fatigue' is irrelevant.

What do the terms CFIDS, ME/CFS, CFS/ME, Myalgic Encephalopathy and ME-CFS mean?

When the terms CFS, CFIDS, ME/CFS, CFS/ME, or Myalgic Encephalopathy are used, what is being referred to may be patients with any combination of:

1. Miscellaneous psychological and non-psychological fatigue states (including somatisation disorder).
2. A self limiting post-viral fatigue state or syndrome (e.g. following glandular fever).
3. A mixed bag of unrelated, misdiagnosed illnesses (each of which features fatigue as well as a number of other common symptoms; poor sleep, headaches, muscle pain etc.) including Lyme disease, multiple sclerosis, Fibromyalgia, athletes over-training syndrome, depression, burnout, systemic fungal infections (candida) and even various cancers.
4. Myalgic Encephalomyelitis patients.

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.*

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 at least 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 qualifies for a 'CFS' 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, sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with M.S., Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological and other M.E. symptoms. Fatigue is not a defining or even essential symptom of M.E. People with M.E. would give anything to be only '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.

The only thing that makes any sense is for patients with M.E. to be studied ONLY under the name Myalgic Encephalomyelitis, and for this term ONLY to be used to refer to a 100% M.E. patient group. The only correct name for this illness – M.E. as per Ramsay/Richardson/Dowsett and Hyde – is Myalgic Encephalomyelitis. M.E. is not synonymous with ‘CFS’, nor is it a subgroup of ‘CFS’. It is also important that the only terms which are used are those which do have an official and correct World Health Organization classification.

There is no such disease as ‘CFS’ – the name ‘CFS’ and the bogus disease category of ‘CFS’ must be abandoned, along with the use of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ ‘CFIDS’, ‘Myalgic Encephalopathy’ and others, for the benefit of all the patient groups involved.

- For more information on the name Myalgic Encephalomyelitis (and the problems with some of these other terms including Myalgic ‘Encephalopathy’) see: [Who benefits from 'CFS' and 'ME/CFS'?](#), and [On the Name Myalgic Encephalomyelitis](#) for more information.
- For more information on why the bogus disease category of 'CFS' must be abandoned, (along with the use of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ ‘CFIDS’ and ‘Myalgic Encephalopathy’ and others), see: [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, plus The misdiagnosis of CFS, Why the disease category of ‘CFS’ must be abandoned and Smoke and Mirrors](#)
- *A 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. M.E. and CFS are not the same, only a small percentage of those (mis)diagnosed with CFS qualify for a diagnosis of authentic M.E., the vast majority do not. People with depression, Lyme disease, Candida, etc. do not need to be given an additional misdiagnosis of ME/CFS, they must instead be given a correct diagnosis finally.

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 and the newer version titled the International Consensus Criteria (ICC) are not accurate M.E. definitions. They are not definitions of M.E. at all. They are both redefinitions of ‘CFS’ which unscientifically add in a few facts about M.E. and by doing so unhelpfully worsen the confusion between these two very different entities. Read more about the benefits and the limitations of the Canadian Guidelines and the ICC at: [Canadian Guidelines Review and Testing for M.E.](#))

What does the term ICD-CFS mean?

The various definitions of ‘CFS’ do not define M.E. Myalgic Encephalomyelitis as 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 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 problematic 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.

Problems with ‘CFS’ or so-called ‘ICD-CFS’ research

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. 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'

- 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 M.E. into context and A warning on 'CFS' and 'ME/CFS' research and advocacy

What does define M.E.? What is its symptomatology?

M.E. is a systemic acutely acquired illness, initiated by a virus infection, which is characterised by post encephalitic damage to the brain stem (CNS) - 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 injured at several levels; these include the cortex, the limbic system, the basal ganglia, the hypothalamus as well as areas of the spinal cord and its appendages. This persisting multilevel 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.

M.E. represents an acute change in the balance of neuropeptide messengers, and consequently, a resulting loss of the ability of the CNS to adequately receive, interpret, store and recover information which enables it to control vital body functions (cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance etc). It is 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 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.

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 CNS – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems in M.E.

M.E. affects the body systemically. Even minor levels of physical and cognitive activity, sensory input and orthostatic stress beyond an M.E. patient's individual post-illness limits causes a worsening of the illness, and of symptoms, which can persist for days, weeks, months or even longer. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (e.g. to the heart), disease progression and/or death in M.E.

M.E. is not stable from one hour, day, week or month to the next. It is the combination of the chronicity, the dysfunctions, the instability and the lack of dependability of these functions that creates the high level of disability in M.E. It is also worth noting that of the CNS dysfunctions, cognitive dysfunction is a major disabling characteristic of M.E.

All of this is not simply theory, but is based upon an enormous body of mutually supportive clinical information. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on (Chabursky et al. 1992 p. 20) (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Hyde 2009) (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).

- *What is Homeostasis?* Homeostasis is the property of a living organism, to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits.

What are some of the symptoms of M.E.?

More than 64 distinct symptoms have been authentically documented in M.E. At first glance it may seem that every symptom possible is mentioned, but although people with M.E. have a lot of different minor symptoms because of the way the central nervous system (which controls virtually every bodily system) is affected, the major symptoms of M.E. really are quite distinct and almost identical from one patient to the next. (Hooper & Montague 2001a, [Online]) (Hyde 2006, [Online])

Individual symptoms of M.E. include:

Sore throat, chills, sweats, low body temperature, low grade fever, lymphadenopathy, muscle weakness (or paralysis), muscle pain, muscle twitches or spasms, gelling of the joints, hypoglycaemia, hair loss, nausea, vomiting, vertigo, chest pain, cardiac arrhythmia, resting tachycardia, orthostatic tachycardia, orthostatic fainting or faintness, circulatory problems, ophthalmoplegia, eye pain, photophobia, blurred vision, wavy visual field, and other visual and neurological disturbances, hyperacusis, tinnitus, alcohol intolerance, gastrointestinal and digestive disturbances, allergies and sensitivities to many previously well-tolerated foods, drug sensitivities, stroke-like episodes, nystagmus, difficulty swallowing, weight changes, paresthesias, polyneuropathy, proprioception difficulties, myoclonus, temporal lobe and other types of seizures, an inability to maintain consciousness for more than short periods at a time, confusion, disorientation, spatial disorientation, disequilibrium, breathing difficulties, emotional lability, sleep disorders; sleep paralysis, fragmented sleep, difficulty initiating sleep, lack of deep-stage sleep and/or a disrupted circadian rhythm.

Neurocognitive dysfunction may include cognitive, motor and perceptual disturbances. Cognitive dysfunction may be pronounced and may include: difficulty or an inability to speak (or understand speech), difficulty or an inability to read or write or to do basic mathematics, difficulty with simultaneous processing, poor concentration, difficulty with sequencing, and problems with memory including difficulty making new memories, difficulty recalling formed memories and difficulties with visual and verbal recall (e.g. facial agnosia). There is often a marked loss in verbal and performance intelligence quotient (IQ) in M.E. (Bassett 2010, [Online]).

- For a more complete symptom list see: [The ultra-comprehensive M.E. symptom list](#). See also: [What it feels like to have M.E.: A personal M.E. symptom list and description of M.E.](#)
- See the [Research and Articles](#) section for many hundreds of different articles and medical studies into M.E.

What other features define or characterise M.E.?

What characterises M.E. every bit as much as the individual neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress;. -n other words, the pattern of symptom exacerbations, relapses and disease progression.

The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the CNS , this characteristic is one of the defining features of the illness and must be present for a correct diagnosis of M.E. to be made. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression in M.E. include the following:

- A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute, sudden change. M.E. patients can only achieve 50% or less of their pre-illness activity levels.
- B. People with M.E. are limited in how physically active they can be but are also limited in similar ways with cognitive exertion, sensory input and orthostatic stress.
- C. When a person with M.E. is active beyond their individual physical, cognitive, sensory or orthostatic limits, there is a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
- D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress that is needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient's pre-illness tolerances and abilities.
- E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
- F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours or more later.
- G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression or death.

- H. The activity limits of M.E. are not short term: an increase in activity levels beyond a patient's individual limits, even if gradual, causes relapse, disease progression or death.
 - I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not caused only by overexertion: there is also a base level of illness which can be quite severe even at rest.
 - J. Repeated overexertion can harm the patient's chances for future improvement in M.E. Patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
 - K. Not every M.E. sufferer has 'safe' activity limits within which they will not exacerbate their illness: this is not the case for very severely affected patients.
- For the full-length version of this text and for a full list of references for this text see: [The ultra-comprehensive M.E. symptom list](#).

What causes M.E.?

M.E. expert [Dr Byron Hyde](#) explains that:

[The] prodromal phase is associated with a short onset or triggering illness. This onset illness usually takes the form of either, or any combination, of the following, (a) an upper respiratory illness, (b) a gastrointestinal upset, (c) vertigo and (d) a moderate to severe meningitic type headache. The usual incubation period of the triggering illness is 4-7 days. The second and third phases of the illness are usually always different in nature from the onset illness and usually become apparent within 1-4 weeks after the onset of the infectious triggering illness (1998 [Online]).

Despite popular opinion, (and the vast amount of 'CFS' government and media propaganda which purports to be relevant to M.E. but is not), there is **no** link between contracting M.E. and being a 'perfectionist' or having a 'type A' or over-achieving personality. M.E. **cannot** be caused by a period of long-term or intense stress, trauma or abuse in childhood, becoming run-down, working too hard or not eating healthily. M.E. is not a form of 'burnout' or nervous exhaustion, or the natural result of a body no longer able to cope with long-term stress.

Research also shows that it is simply not possible that M.E. could be caused by the Epstein-Barr virus, any of the herpes viruses (including HHV6), glandular fever/mononucleosis, Cytomegalovirus (CMV), Ross River virus, Q fever, hepatitis, chicken pox, influenza or any of the bacteria which can result in Lyme disease (or other tick-borne bacterial infections). M.E. is also not a form of chemical poisoning.

M.E. is undoubtedly caused by a virus, a virus with an incubation period of 4-7 days. There is also ample evidence that M.E. is caused by the same type of virus that causes polio: an enterovirus (Hyde 2006, [Online]) (Hyde 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Ryll 1994, [Online]).

- See [The outbreaks \(and infectious nature\) of M.E.](#) section for more information.
- For information on the outrageous hype surrounding the recent XMRV 'CFS' research, please see the [XMRV, 'CFS,' and M.E.](#) paper by Sarah Shenk as well as the HFME press release: [International M.E. expert disputes that 'CFS' XMRV retrovirus claim has relevance to M.E. patients](#)

Are there outbreaks of M.E.?

One of the most fundamental facts about M.E. throughout its history is that it occurs in epidemics. 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, 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 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 (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]).

M.E. is an infectious neurological disease and represents a major attack on the CNS by the chronic effects of a viral infection. The world's leading M.E. experts, namely Ramsay, Richardson, Dowsett and Hyde, (and others) have all indicated that M.E. is caused by an enterovirus.

The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling (Hyde 2007, [Online]) (Hyde 2006, [Online]). An enterovirus explains the age variation, sex variation, obvious resistance of some family members to the infection and the effect of physical activity -particularly in the early stages of the illness- in creating more long-term/severe M.E. illness in the host (Hyde & Jain 1992a, p. 40).

There is also the evidence that:

- M.E. epidemics very often followed polio epidemics.
- M.E. resembles polio at onset.
- Serological studies have shown that communities affected by an outbreak of M.E. were effectively blocked (or immune) from the effects of a subsequent polio outbreak.
- Evidence of enteroviral infection has been found in the brain tissue of M.E. patients at autopsy. (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]).

The US Centres for Disease Control (CDC) placed 'CFS' on its "Priority One, New and Emerging" list of infectious diseases some years ago; a list that also includes Lyme disease, hepatitis C, and malaria' (Gellman & Verillo 1997, p. 19). Despite this, no real research into transmissibility (or more importantly on reducing infection rates) has been done by any government on patients with M.E. (or even 'CFS') despite ample evidence that this is an infectious disease.

There have been many well-documented clusters or outbreaks of the illness, reports of as many as 4.5% of M.E. sufferers contracting the illness immediately after blood transfusions (or after needle-stick injuries involving the blood of M.E. patients) and evidence of the disease spreading through casual contact amongst family members (Johnson, 1996) (Carruthers et al. 2003, p.79).

As Dr Elizabeth Dowsett explains: 'The problem we face is that, in spite of overwhelming epidemiological and technical evidence of an infectious case, the truth is being suppressed by the government and the 'official' M.E. charities as 'too scary' for the general public' (n.d.a, [Online]).

This pretence of ignorance on behalf of government worldwide has had enormous consequences: for example, only in the UK are people with M.E. specifically banned from donating blood. Consequently, the number of people infected with M.E. continues to rise unabated and largely unnoticed by the public.

- See: [The outbreaks \(and infectious nature\) of M.E.](#) page for more information.

Is M.E. difficult to diagnose? What tests can be used to diagnose 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. There is just no other illness that has all the major features of M.E.

Although there is as yet no single test which can be used to diagnose M.E., there are (as with Lupus, Multiple Sclerosis, ovarian cancer and many other illnesses) 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 (e.g. brain scans), then a diagnosis of M.E. cannot be correct (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hooper et al. 2001, [Online]) (Chabursky et al. 1992, p.22).

As M.E. expert Dr Byron Hyde explains:

The one essential characteristic of M.E. is acquired CNS dysfunction. A patient with M.E. is a patient whose primary disease is CNS change, and this is measurable. We have excellent tools for measuring these physiological and neuropsychological changes: SPECT, xenon SPECT, PET, and neuropsychological testing (2003, [Online]).

Tests which together can be used to confirm an M.E. diagnosis include:

- SPECT and xenon SPECT scans of the brain
- MRI and PET scans of the brain
- Neurological examination
- Neuropsychological testing (including QEEG scans)
- The Romberg or tandem Romberg test
- Various tests of the immune system (including tests of natural killer cells number and function)
- Insulin levels and glucose tolerance tests
- Sedimentation rate testing (M.E. is one of less than half a dozen diseases which can cause sedimentation rates as low as zero)
- Circulating blood volume tests (which may show a reduced circulating blood volume of up to 50%)
- 24 hour Holter monitor testing (a type of heart monitor)
- Tilt table examination and blood pressure tests
- Exercise testing and chemical stress tests
- Physical exam

These tests are the most critical in the diagnosis of M.E., although various other types of tests are also useful.

Dr Byron Hyde's highly regarded (and TESTABLE) M.E. definition [The Nightingale Definition of M.E.](#) makes diagnosis easier than ever before, even for those with no experience with the illness (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett n.d., [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92).

- See [Testing for M.E.](#) for more information on the various tests which can aid M.E. diagnosis. See also: [Are we just 'marking time?'](#)
- Objective scientific tests *are* available which can aid in the diagnosis of M.E. and easily prove the severe abnormalities across many different bodily systems seen in M.E. Unfortunately many patients are not given access to these tests. Problems also exist with doctors not being familiar with the abnormalities on testing seen in M.E. and so misinterpreting the results of some tests. The problem is not that these tests don't exist, but that doctors – and many patients – are unaware of this information on testing, that it is not generally accepted due to the nefarious influence of political and financial vested interest groups, and that there are overwhelming financial and political incentives for researchers to IGNORE this evidence in favour of the bogus 'CFS' (or 'subgroups of 'ME/CFS') construct. For more information on the lack of access to appropriate testing for M.E. patients see: [The Montague/Hooper Paper](#) and [Testing for M.E.](#)

How common is M.E.? Who gets M.E. and how?

Although the illness we now know as M.E. has existed for centuries, for much of that time it was a relatively uncommon disease. Following the mass polio vaccination programs of the 1960s, cases of polio were greatly reduced and outbreaks of M.E. seemed to be similarly affected. It wasn't until the late 1970s that M.E. began its dramatic increase in incidence worldwide. Over 20 years later, M.E. is a worldwide epidemic of devastating proportions. Many people have died from M.E. and there are now many hundreds of thousands of people severely disabled by this epidemic (TCJRME 2007, [Online]) (Hyde 1992, p. xi).

The main period of infectivity of M.E. peaks at the time just before symptoms appear through to the initial acute phase of the illness (which lasts for several months or in some cases years). M.E. appears to be highly infective but also highly selective. The major mode of infectivity is by an airborne or respiratory route. Modes of transmission are thought to include: casual contact (respiratory), salivary transmission (e.g. kissing), sexual transmission and transmission through blood products (Hyde et al. 1992, pp. 25 - 37). (A recent study of 752 patients found that 4.5% of them – almost one in twenty – had had a blood transfusion days or a week before experiencing acute onset of M.E.) (Carruthers et al. 2003, [Online]) (Hyde et al. 1992, pp. 25 - 37).

M.E. has a similar strike rate (or possibly somewhat higher), to Multiple Sclerosis and is estimated to affect roughly 0.2% of the population. Children and teenagers are also susceptible to the illness and children as young as five have been diagnosed with M.E. (M.E. can occur in children younger than five, but this is thought to be rare.)

All ages are affected but most commonly sufferers are under 45 at onset. Women are affected around three times as often as men, a ratio common in autoimmune disorders, although in children the sexes seem to be afflicted equally.

M.E. affects all ethnic and socio-economic groups and has been diagnosed all over the world. There are more than a million M.E. sufferers worldwide (Hooper et al. 2001 [Online]) (Hyde 1992, pp. x - xxi).

- The CDC has recently released vastly inflated estimates for figures affected by 'CFS' but it should be noted that the number of people suffering with sustained fatigue has no more relevance to patients with M.E. than to those with M.S. or AIDS or any other distinct illness. see: [More medical 'firsts' from the CDC?](#)

Are there any treatments for M.E.?

There are no easy or quick cures for M.E., nor are any on the horizon – despite a lot of hype about various fairly unpromising 'CFS' research endeavours. Intelligent nutritional, pharmaceutical and other interventions can make a significant difference to a patient's life, however.

Appropriate biomedical diagnostic testing should be done as a matter of course (and repeated regularly) to ensure that the aspects of the illness which are able to be treated *can* be diagnosed, monitored and then treated as appropriate. Testing is also important so that dangerous deficiencies and dysfunctions, which may place the patient at significant risk, are not overlooked (Hooper et al. 2001 [Online]).

For specific information on M.E. treatment, the following HFME papers are recommended reading:

- [Treating M.E. - The basics](#) and [Treating and living with M.E.: Overview](#)
- [Finding a good doctor when you have M.E.](#)
- [Symptom-based management vs. deep healing in M.E.](#)
- [A quick start guide to treating and improving M.E. with aggressive rest therapy, diet, toxic chemical avoidance, medications, supplements and vitamins](#)
- [Why research and try treatments when some groups claim an M.E. cure is coming soon?](#)
- [What if vitamin/mineral/protocol 'x' didn't work for me?](#)
- [Deep healing in M.E.: An order of attack!](#)
- [Treating M.E. in the early stages](#)

What is known about M.E. so far?

There is an abundance of research which shows that M.E. is an organic illness which can have profound effects on many bodily systems. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on. More than a **thousand** good articles now support the basic premises of M.E. Autopsies have also confirmed such reports of bodily damage and infection (Hooper & Williams 2005a, [Online]).

Many different organic abnormalities have been found in M.E. patients (in peer reviewed research). Patient advocates [Margaret Williams](#) and [Eileen Marshall](#) explain that:

- There is evidence of disrupted biology at cell membrane level
- There is evidence of abnormal brain metabolism
- There is evidence of widespread cerebral hypoperfusion
- There is evidence of CNS and immune dysfunction
- There is evidence of CNS inflammation and demyelination
- There is evidence of hypomyelination
- There is evidence that M.E. is a complex, serious multi-system autoimmune disorder
- There is evidence of significant neutrophil apoptosis

- There is evidence that the immune system is chronically activated (e.g. the CD4:CD8 ratio may be grossly elevated)
- There is evidence that natural killer (NK) cell activity is impaired (i.e. diminished)
- There is evidence that the vascular biology is abnormal, with disrupted endothelial function
- There is novel evidence of significantly elevated levels of isoprostanes
- There is evidence of cardiac insufficiency and that patients are in a form of cardiac failure (which is exacerbated by even trivial levels of physical activity, cognitive activity and orthostatic stress)
- There is evidence of autonomic dysfunction (especially thermoregulation; frequency of micturition with nocturia; labile blood pressure; pooling of blood in the lower limbs; reduced blood volume (with orthostatic tachycardia and orthostatic hypotension. Findings of a circulating blood volume of only 75% of expected are common, and in some patients the level is only 50% of expected.)
- There is evidence of respiratory dysfunction, with reduced lung function in all parameters tested
- There is evidence of neuroendocrine dysfunction (notably HPA axis dysfunction)
- There is evidence of recovery rates for oxygen saturation that are 60% lower than those in normal controls
- There is evidence of delayed recovery of muscles after exercise (affecting all muscles including the heart.)
- There is evidence of a sensitive marker of muscle inflammation
- There is evidence that the size of the adrenal glands is reduced by 50%, with reduced cortisol levels
- There is evidence of at least 35 abnormal genes, (these are acquired genetic changes, not hereditary), specifically those that are important in metabolism; there are more abnormal genes in M.E. than there are in cancer
- There is evidence of serious cognitive impairment(worse than occurs in AIDS dementia.)
- There is evidence of adverse reactions to medicinal drugs, especially those acting on the CNS.
- There is evidence that symptoms fluctuate markedly from day to day and even from hour to hour (2006, [Online])

Note that this is only a sample of some of the research available, not an exhaustive list.

It is known that M.E. is:

1. An acute onset (biphasic) epidemic or endemic infectious disease process
2. An autoimmune disease (with similarities to Lupus)
3. An infectious neurological disease, affecting adults and children
4. A disease which involves significant (and at times profound) cognitive impairment/dysfunction
5. A persistent viral infection (due to an enterovirus; the same type of virus which causes poliomyelitis and post-polio syndrome)
6. A diffuse and measurable injury to the vascular system of the CNS.
7. A CNS disease with similarities to M.S.
8. A variable (but always serious) diffuse, acquired brain injury
9. A systemic illness (associated with organ pathology; particularly cardiac)
10. A vascular disease
11. A cardiovascular disease
12. A type of cardiac insufficiency
13. A mitochondrial disease
14. A metabolic disorder
15. A musculo-skeletal disorder
16. A neuroendocrine disease
17. A seizure disorder
18. A sleep disorder

19. A gastrointestinal disorder
20. A respiratory disorder
21. An allergic disorder
22. A pain disorder
23. A life-altering disease
24. A chronic or lifelong disease associated with a high level of disability
25. An unstable disease: from one hour/day/week or month to the next
26. A potentially progressive or fatal disease

M.E. affects every cell in the body and almost every bodily system (Hyde 2007, [Online]) (Hooper et al. 2001, [Online]) (Cheney 2007, [video recording]) (Ramsay 1986, [Online]).

- For more information see the [General articles and research overviews](#) section. See also articles by: [Dr. Elizabeth Dowsett](#) and [Byron Hyde MD.](#)

Is there a legitimate scientific debate about whether or not M.E. is a 'real' neurological disease?

Despite popular opinion there simply is no legitimate scientifically motivated debate about whether or not M.E. is a 'real' neurological illness or not, or whether it has a biological basis.

The psychological or behavioural theories of M.E. and claims that M.E. is just another term for 'CFS' are no more scientifically viable than theories of a flat earth. They are pure fiction.

- For more information see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Smoke and Mirrors](#) and [Putting research and articles on M.E. into context.](#)

Are there any somewhat similar medical conditions?

There are a number of post-viral fatigue states or syndromes which may follow common infections such as mononucleosis/glandular fever, hepatitis, Q fever, Ross river virus and so on. M.E. is an entirely different condition to these self-limiting fatigue syndromes however, and it is *not* caused by the Epstein Barr virus or any of the herpes or hepatitis viruses. People suffering with any of these post-viral fatigue syndromes do not have M.E.

M.E. does have some limited similarities – to varying degrees – to illnesses such as multiple sclerosis, Lupus, post-polio syndrome, Gulf War Syndrome and chronic Lyme disease, and others. But this does not mean that they represent the same etiological or pathobiological process. They do not.

M.E. is a distinct neurological illness with a distinct onset, symptoms, aetiology, pathology, response to treatment, long and short term prognosis, and World Health Organization classification (G.93.3) (Hyde 2006, [Online]) (Hyde 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online])

- See [M.E. and other illnesses](#) for more information. See also the new paper: [M.E. vs. M.S.: Similarities and differences.](#)

How well is research into M.E. research funded by government?

Governments around the world are currently spending \$0 a year on M.E. research. Considering the severity of the illness and the vast numbers of patients involved, this is a worldwide disgrace.

- See [Putting research and articles on M.E. in context](#) and [A warning on 'CFS' and 'ME/CFS' research and advocacy](#) for more information about research into M.E. and the challenges involved. See the [Donations](#) page on the HFME website to make a donation towards M.E. research and advocacy.

Abuse and M.E.

Two of the most common interventions people with M.E. are encouraged to participate in are cognitive behavioural therapy (CBT) and graded exercise therapy (GET).

However, despite the misleading claims to the contrary made by various vested interest groups, no evidence exists which demonstrates that CBT and GET are appropriate, effective or safe treatments for M.E. patients. Studies by these groups (and others) involving miscellaneous psychiatric and non-psychiatric ‘fatigue’ sufferers, and their positive response to these treatments, have no more relevance to M.E. sufferers than they do to patients with Multiple Sclerosis, diabetes or any other illness. Patients with M.E. are routinely being prescribed these treatments on what amounts to a random basis medically.

As (very bad) luck would have it, graded exercise programs are probably the single most inappropriate ‘treatment’ that an M.E. sufferer could be encouraged to undertake. Permanent damage may result, as well as disease progression. Patient accounts of leaving exercise programs much more severely ill than when they began them are common: some end up wheelchair-bound, bed-bound or requiring hospitalisation in intensive care or cardiac care units. The damage caused is often severe and either long-term or permanent: some patients are still dealing with the effects of inappropriate advice to exercise five, ten or more YEARS afterwards, and for some patients this damage is permanent. Sudden deaths have also been reported in a small percentage of M.E. patients following exercise.

CBT and GET are at best useless and at worst extremely harmful for M.E. patients. Despite this, these ‘treatments’ are regularly recommended for people with M.E., who are assured that they are completely safe. Patient participation is not always voluntary. Many M.E. patients have been treated as psychiatric patients against their will (or against their parents’ will in the case of children with M.E.). In some cases it is a condition of receiving medical insurance or government welfare entitlements that M.E. patients first undergo ‘rehabilitation’, including CBT and GET programs, particularly in the UK.

If a prescription drug had anything like the appalling track record exercise has with people with M.E. (or even a small fraction of it, even 2%) it would be a worldwide scandal. The drug would be immediately banned, there would be some form of inquiry and serious criminal charges may well be laid. Yet the rate of people with M.E. encouraged or even *forced* to exercise continues to rise, and with the full support of governments. This is despite the fact that legitimate research clearly shows that along with the huge risk involved, it has a ZERO percent chance of providing any benefit to people with authentic M.E. That this can be allowed to go on in such a supposedly enlightened day and age as ours defies belief.

It is also of great concern that so many M.E. patients are ONLY offered ‘treatments’ such as CBT and GET, while access to even basic appropriate medical care is withheld. Of the 25% of patients who are severely affected by the illness (and are bed-bound and housebound), the majority have no contact with the health service at all as they are seldom able to obtain house calls (Dunn 2005, [Online]). Many sufferers are also refused the basic welfare support to which they are entitled.

Thus a significant percentage of very physically ill and vulnerable M.E. patients are simply left to suffer and die at home without any medical care, welfare or social support (Hooper 2003a, [Online]).

- These brief comments on the effects of CBT and GET are taken from the more detailed paper: [The effects of CBT and GET on patients with M.E.](#), see this paper for more information.
- For more information about the effects of overexertion on M.E. patients, including statements/research from some of the world’s leading M.E. experts about why overexertion is so physically harmful, see: [Smoke and Mirrors](#). (This paper also includes links to patient accounts of the effects of overexertion on people with M.E.).
- A recent example of an M.E. sufferer being taken into psychiatric care against their will is the case of Sophia Mirza, in the UK. Tragically, Sophia died of her illness after being wrongly sectioned under the Mental Health Act. Sophia was severely ill and bedbound but she was refused even basic medical care, and this is believed to have contributed greatly to her death. For more information on this tragic case and entirely avoidable death, see: [Inquest Implications](#), [Civilization: Another word for barbarism](#) and [The Story of Sophia and M.E.](#)
- For more information about forced exercise ‘treatments’ see the 100+ page [CBT and GET Database](#). See also [Comments on the 'Lightning Process' scam and other related scams aimed at M.E. patients](#)

Is it only M.E. patients who are negatively affected by the bogus creation of ‘CFS’?

If only. Vast numbers of patients from all sorts of varied patient groups misdiagnosed as ‘CFS’ are also denied appropriate diagnosis and treatment, and may routinely be subjected to inappropriate psychological interventions such as CBT and GET. the ‘CFS’ insurance company scam also impacts negatively on doctors and the general public.

the only groups which gain from the 'CFS' confusion are insurance companies and various other organisations and corporations, including the government, which have a vested financial interest in how these patients are treated. For more information see: [The misdiagnosis of 'CFS'](#) and [Who benefits from 'CFS' and 'ME/CFS'?](#)

How severe is M.E.?

Although some people do have more moderate versions of the illness, symptoms are extremely severe for at least 25-30% of the people who have M.E., significant numbers of whom are housebound and bedbound.

Dr. Paul Cheney stated before a US FDA Scientific Advisory Committee:

I have evaluated over 2,500 cases. At worst, it is a nightmare of increasing disability with both physical and neurocognitive components. The worst cases have both an M.S.-like and an AIDS-like clinical appearance. We have lost five cases in the last six months. 80% of cases are unable to work or attend school. We admit regularly to hospital with an inability to care for self (Hooper et al. 2001 [Online]).

M.E. patients have been found to experience greater functional severity than the studied patients with heart disease, virtually all types of cancer, and all other chronic illnesses.

In the 1980s Mark Loveless, an infectious disease specialist and head of the AIDS and M.E. Clinic at Oregon Health Sciences University, found that M.E. patients whom he saw had far lower scores on the Karnofsky performance scale than his HIV patients even in the last week of their life. He testified that an M.E. patient, 'feels effectively the same every day as an AIDS patient feels two weeks before death' (Hooper & Marshall 2005a, [Online]).

But in M.E., this extremely high level of illness and disability is not short-term. it does not always lead to death and it can instead continue uninterrupted for **decades**.

- For more information on severe M.E. see [The severity of M.E.](#) and [M.E. fatalities](#) and [Why patients with severe M.E. are housebound and bedbound](#)
- Patients with M.E. may also find the following papers useful: [Adjusting personal care tasks for the M.E. patient](#) and [The HFME M.E. ability and severity scale checklist](#)
- If you would like a friend or family member to be included in the HFME M.E. memorial list, please see the [HFME memorial lists](#) page for contact details, and for further information.
- It should also be noted that even those patients with moderate M.E. are far more affected than many patients with a variety of other illnesses. Of course severe M.E. is even worse, but moderate M.E. can also cause significant symptoms and a relatively higher level of disability and suffering than many other illnesses.

Recovery from M.E.

M.E. patients who are given advice to rest in the early stages of the illness, and who avoid overexertion thereafter, have repeatedly been shown to have the most positive long-term prognosis.

As M.E. expert Dr Melvin Ramsay explains:

The degree of physical incapacity varies greatly, but the [level of severity] is directly related to 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**. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them (1986, [Online]).

M.E. can be progressive, degenerative (change of tissue to a lower or less functioning form, as in heart failure), chronic, or relapsing and remitting. Some patients experience spontaneous remissions- albeit most often at a greatly reduced level of functioning compared to pre-illness- and such patients remain susceptible to relapses for the remainder of their lives. M.E. is a chronic/life-long disability where relapse is always possible. Cycles of severe relapse are common, as are further symptoms developing over time. Around 30% of cases are progressive and degenerative and sometimes M.E. is fatal.

As Dr Elizabeth Dowsett writes:

After a variable interval, a multi-system syndrome may develop, involving permanent damage to skeletal or cardiac muscle and to other "end organs" such as the liver, pancreas, endocrine glands and lymphoid tissues, signifying the further development of a lengthy chronic, mainly neurological condition with evidence of metabolic dysfunction in the brain stem. Yet, stabilisation, albeit at a low level, can still be achieved by appropriate management and support.

The death rate of 10% occurs almost entirely from end-organ damage within this group (mainly from cardiac or pancreatic failure) (2001a, [Online]).

Clearly, many people with M.E. are significantly or severely disabled. But what is so tragic about this high level of suffering is that so much of it is needless. The appropriate support (financial, medical and practical) can do much to prevent the physical, occupational and deterioration in quality of life for M.E. patients and can stabilise the illness (Dowsett 2002b, [Online]).

Many deaths from M.E. could have been prevented if only those patients had been given a basic level of support and care made available to patients with illnesses with comparable care needs such as M.S. and Motor Neurone Disease.

- The 3 Part M.E. Ability and Severity Scale can be used to measure M.E. severity over time.
- See Treating M.E. for more information on the importance of avoiding overexertion in M.E. See also Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound.
- For information on adrenaline surges in M.E., and the different order in which certain bodily systems may be affected by M.E. (and by overexertion), see the Dr Cheney section in The effects of CBT and GET on patients with M.E. or The importance of avoiding overexertion in M.E. (Note that Dr Cheney does unfortunately mix M.E. and 'CFS' information and so cannot be considered an M.E. expert, as such.)

Conclusion

Certain groups and individuals are benefiting enormously from this fraudulent artificial 'CFS' construct.

To say that these groups and individuals always believe what they are saying and that it is based on science or reality is ridiculous. To say that it is merely a misunderstanding or a mistake is equally ridiculous. The 'CFS' construct is a complete fiction, and exists purely because it is so financially and politically beneficial to a number of powerful groups.

The artificial 'CFS' construct is no more a scientifically accurate description of M.E. than it is a scientifically accurate description of M.S., Lupus or polio. This pretence of ignorance about M.E. and about the reality of 'CFS', particularly by governments, has had devastating consequences for people with M.E. – as well as all of those with non-M.E. illnesses who are misdiagnosed as having 'CFS' – and has also meant that the number of M.E. sufferers continues to rise unabated and largely unrecognised. The general public worldwide, including sufferers themselves, has been lied to repeatedly about the reality of M.E.

The continuing, decades old, systemic abuse and neglect of the million or more people with M.E. worldwide has to stop. M.E. and 'CFS' are *not* the same. Concepts such as 'ME/CFS,' 'CFS/ME,' Myalgic 'Encephalopathy' and 'CFIDS' are also unhelpful, unscientific and only add to the obfuscation.

'CFS' is merely a scam invented by insurance companies motivated by profit without regard for truth or ethics. These groups are acting without any regard for the extreme suffering and avoidable deaths they are causing. These groups are acting criminally. The scam is tissue thin and very easily discovered if one merely takes the time to look at the evidence.

Why is almost nobody doing this? Why is the world letting these groups get away with such a heinous scam and such appalling abuse on a massive scale? Why isn't the world caring enough or smart enough or gutsy enough to see through these slick, well-funded misinformation campaigns, and to act? How can this be, when the lies are so flimsy and scientifically laughable? Have we learned nothing from the devastating corporate cover-ups of the truth about tobacco and asbestos in our recent past? Where is the World Health Organisation? Where are our human rights groups? Where is our media? Where are our uncompromising investigative journalists?

Will it take another 20 years? How much more extreme do the suffering and abuse have to be? How many more hundreds of thousands of children and adults worldwide have to be affected? How many more patients will have to die needlessly before something is finally done? How much longer will we leave the fox in charge of the hen house? It's insupportable.

Where do we go from here?

Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. would achieve nothing and create yet more confusion and mistreatment. The problem

is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with 'CFS' actually *do* have psychological illnesses.

There is no such distinct disease as 'CFS' – that is the entire issue, and the vast majority of patients misdiagnosed with 'CFS' do not have M.E. and so have no more right to that term than to 'cancer' or 'diabetes.' The only way forward, for the benefit of society and every patient group involved, is that:

1. The bogus disease category of 'CFS' must be abandoned completely. 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, and not given a meaningless 'CFS' misdiagnosis. Patients with M.E. need this same opportunity. Each of the patient groups involved must be correctly diagnosed and treated as appropriate, based on legitimate and unbiased scientific evidence involving the SAME patient group.

2. The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. (as a distinct neurological disease) must be accepted and adhered to in all official documentations and government policy.

As Professor Malcolm Hooper explains:

The term Myalgic Encephalomyelitis 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 current 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])

3. People with M.E. must immediately stop being treated as if they are mentally ill or suffer with a behavioural illness; as if their physical symptoms do not exist or can be improved with 'positive thinking' and exercise, or be mixed in with various 'fatigue' sufferers or patients with any other illness than authentic Myalgic Encephalomyelitis. 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 that which is available for those with comparable illnesses (e.g. M.S. or Lupus). The facts about M.E. must be taught to medical students, and included in mainstream medical journals.

- 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.
- 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' and Problems with the use of 'ME/CFS' by M.E. advocates,
- See also: Problems with 'our' M.E. (or 'CFS' 'CFIDS' or 'ME/CFS' etc.) advocacy groups (also available in an animated video format.)

What can you do to help?

Unlike people with HIV/AIDS, people with M.E. do not have an initial period of their illness where they are only mildly affected. M.E. is severely disabling even in the first week of illness. People with M.E. are almost all far too ill to stage protests, rallies or marches. Many with M.E. cannot even read enough to be able to understand what is happening, and are not even aware that high quality scientific information on M.E. exists and that supporting the various 'CFS' and 'ME/CFS' faux 'advocacy' groups is counter-productive in the extreme.

Almost all so-called patient advocacy groups worldwide have sold patients out to the highest bidder and are now actively *collaborating* with our abusers. These groups are no longer advocates for patients with M.E. – indeed they are working directly AGAINST the interest of people with M.E. These groups also do not help all those misdiagnosed with 'CFS', who do not have M.E. The media too has sold-out and betrayed M.E. patients.

People with M.E. have only a tiny minority of the medical, scientific, legal and other potentially supporting professions, as well as the public, on their side.

The Committee for Justice and Recognition of Myalgic Encephalomyelitis explains:

There is no immunity to M.E. The next victim of this horrible disease could be your sister, your friend, your brother, your grandchildren, your neighbour [or] your co-worker. M.E. is an infectious disease that has become a widespread epidemic that is not going away. We must join together, alert the public and demand action (2007, [Online]).

That is what is needed – people power. Educated people power. For people from all over the world to stand up for M.E. Individual physicians, journalists, politicians, human rights campaigners, patients, families and friends of patients and the public, whether they are affected yet by M.E. or not, must stand up for the truth. That is the only way change will occur- through education and people simply refusing to accept what is happening any more.

Yes, there are powerful and immensely wealthy vested interest groups out there, who will fight the truth every step of the way, but we have science, reality and ethics on our side and those are also very powerful. However, for this to be of any use to us, we must first make ourselves aware of the facts *and then use them*.

So what you can do to help is to PLEASE spread the truth about M.E. and try to expose the lie of ‘CFS.’ You can also help by NOT supporting the bogus concepts of ‘CFS,’ ‘ME/CFS,’ ‘subgroups of ME/CFS,’ ‘CFS/ME,’ ‘CFIDS’ and Myalgic ‘Encephalopathy.’ Do not support groups which promote these concepts. Do not give public or financial help to our abusers.

The abuse and neglect of so many seriously ill people on such an industrial scale is truly *inhumane* and has already gone on for far too long. People with M.E. desperately need your help.

More information:

- For more information about the medical and political facts of M.E. see: [What is M.E.? Extra extended version](#), [Who benefits from 'CFS' and 'ME/CFS'?](#), [The misdiagnosis of CFS](#), [Why the bogus disease category of ‘CFS’ must be abandoned](#), [Smoke and mirrors](#), [Testing for M.E.](#) and [Putting research and articles on M.E. into context](#).
- If you know someone with M.E. and want to know how to deal with it, and what you can do to help, then please read [So you know someone with M.E.?](#)
- 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.

Acknowledgments

Thanks to Peter Bassett and Lesley Ben for editing this paper.

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) about M.E. Again, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

This paper is intended to provide a brief summary 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 the 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. For a full reference list please see the [References](#) page.

1. Bagnall, Gurli 2006, *Civilization: Another word for barbarism* [Online], Available: <http://www.hfme.org/wbagnall.htm>
2. Bagnall, Gurli 2004, *Myalgic Encephalomyelitis: A slender string to our bow* [Online], Available: <http://www.hfme.org/wbagnall.htm>

3. Bassett, Jodi 2009, The Ultra-Comprehensive Myalgic Encephalomyelitis Symptom List [Online], Available: <http://www.hfme.org/themesymptomlist.htm>
4. Bastien, Sheila PhD. 1992, *Patterns of Neuropsychological Abnormalities and Cognitive Impairment in Adults and Children* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa
5. Bell, David S MD 1995, *The Doctor's Guide to CFIDS*, Perseus Books, Massachusetts
6. Carruthers, Bruce M. et al 2003, *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition*, Haworth Medical Press, New York
7. Chabursky, Borys. Hyde, Byron M.D. & Anil Jain M.D. 1992, *A Description of Patients who Present with a Presumed Diagnosis of M.E.* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa, pp. 19-24
8. Cheney, Paul M.D. 2006, *The Heart of the Matter* [video recording], Available: <http://www.hfme.org/wcheney.htm>
9. Dowsett, Elizabeth MBChB. 2002a, *The impact of persistent enteroviral infection*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
10. Dowsett, Elizabeth MBChB. 2002b, *MEDICAL RESEARCH COUNCIL DRAFT DOCUMENT FOR PUBLIC CONSULTATION*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
11. Dowsett, Elizabeth MBChB. 2001a, *THE LATE EFFECTS OF ME Can they be distinguished from the Post-polio syndrome?* [Online], Available: <http://www.hfme.org/wdowsett.htm>
12. Dowsett, Elizabeth MBChB. 2001b, *A rose by any other name* [Online], Available: <http://www.hfme.org/wdowsett.htm>
13. Dowsett, Elizabeth MBChB. 2000, *Mobility problems in ME* [Online], Available: <http://www.hfme.org/wdowsett.htm>
14. Dowsett, Elizabeth MBChB. 1999a, *Redefinitions of ME* [Online], Available: <http://www.hfme.org/wdowsett.htm>
15. Dowsett, Elizabeth MBChB. 1999b, *Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC CIENCE!*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
16. Dowsett, Elizabeth MBChB. 1998, *Can Hysteria be diagnosed with confidence ? - Conflicts in British Research*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
17. Dowsett, Elizabeth MBChB. n.d. a, *Differences between ME and CFS*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
18. Dowsett, Elizabeth MBChB. n.d. b, *Time to put the exercise cure to rest*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
19. Dowsett, Elizabeth MBChB. n.d. c, *Is Stress more than a modern buzz word?*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
20. Dowsett, Elizabeth MBChB. n.d. d, *Brain problems in ME – is there a simple explanation?*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
21. Dowsett, Elizabeth MBChB. in: Colby, Jane 1996, *ME: The New Plague*, Ipswich Book Company, Ipswich.
22. Dowsett E. & Ramsay, A.M. n.d., *'Myalgic Encephalomyelitis: Then and Now'* *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, B. Hyde (ed.), The Nightingale Foundation, Ottawa, pp. 81-84.
23. Dowsett E., Ramsay A.M., McCartney A.R., & Bell E.J. 1990, *'Myalgic Encephalomyelitis: A persistent Enteroviral Infection?'* in *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, B. Hyde (ed.), The Nightingale Foundation, Ottawa, pp. 285-291.
24. Dunn, Linda (in consultation with the Cross Party Group on ME) 2005, *Myalgic Encephalomyelitis. The impact on sufferers: is health policy in Scotland on the right path?* [Online], Available: [Click here](#).
25. Hooper, M 2006, *Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research* J. Clin. Pathol. published online 25 Aug 2006; doi:10.1136/jcp.2006.042408 Available: <http://www.hfme.org/whooper.htm>
26. Hooper, M. & Marshall E.P. 2005a, *Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis* [Online], Available: <http://www.hfme.org/whooper.htm>Note: This paper is 174 pages in length]
27. Hooper, M. & Marshall E.P. 2005b, *Myalgic Encephalomyelitis: Why no accountability?* [Online], Available: <http://www.hfme.org/whooper.htm>
28. Hooper, M. 2003a, *The MENTAL HEALTH MOVEMENT: PERSECUTION OF PATIENTS? A CONSIDERATION OF THE ROLE OF PROFESSOR SIMON WESSELY AND OTHER MEMBERS OF THE "WESSELY SCHOOL" IN THE PERCEPTION OF MYALGIC ENCEPHALOMYELITIS (ME) IN THE UK* [Online], Available: <http://www.hfme.org/whooper.htm>
29. Hooper, M 2003b, *Engaging with M.E.: Towards Understanding, Diagnosis and Treatment*, University of Sunderland, UK
30. Hooper, M. & Montague S 2001a, *Concerns about the forthcoming UK Chief medical officer's report on Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) notably the intention to advise clinicians that only limited investigations are necessary* (The Montague/Hooper paper) [Online], Available: <http://www.hfme.org/whooper.htm>

31. Hooper, M. & Montague S 2001b, *Concepts of accountability* [Online], Available: <http://www.hfme.org/whooper.htm>
32. Hooper, M. Marshall E.P. & Williams, M. 2001, *What is ME? What is CFS? Information for Clinicians and Lawyers*, [Online], Available: <http://www.hfme.org/whooper.htm>
33. Hooper, M. n.d., *The Terminology of ME and CFS* [Online], Available: <http://www.hfme.org/whooper.htm>
34. Hyde, Byron M.D. 2007, *The Nightingale Definition of Myalgic Encephalomyelitis* [Online], Available: <http://www.hfme.org/whydepapers.htm#390403648>
35. Hyde, Byron M.D. 2006, *A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis & An Irreverent History of Chronic Fatigue Syndrome* [Online], Available: <http://www.hfme.org/whydepapers.htm#390405053>
36. Hyde, Byron M.D. 2003, *The Complexities of Diagnosis* in (ed) Jason, Leonard et al. 2003 *Handbook of Chronic Fatigue Syndrome* by Ross Wiley and Sons, USA. Available: <http://www.hfme.org/whydepapers.htm#390405053>
37. Hyde, Byron M.D. 1998, *Are Myalgic Encephalomyelitis and CFS Synonymous Terms?* [Online], Available: <http://www.hfme.org/whydesynonymousterms.htm>
38. Hyde, Byron M.D. 1992, *Preface* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa.
39. Hyde, Byron M.D. & Anil Jain M.D. 1992, *Clinical Observations of Central Nervous System Dysfunction in Post Infectious, Acute Onset M.E.* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa, pp. 38-65.
40. Hyde, Byron M.D. & Anil Jain M.D. 1992a, *Cardiac and Cardiovascular aspects of M.E.: A Review* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa, pp. 375-383.
41. Hyde, Byron M.D., Bastien S Ph.D. & Anil Jain M.D. 1992, *General Information, Post Infectious, Acute Onset M.E. / CFS* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa, pp. 25-37.
42. Johnson, Hillary 1996, *Osler's Web*, Crown Publishers, New York
43. Jones, Doris M. MSc. 1998, *SOME FACTS AND FIGURES ON CBT, GET AND OTHER APPROACHES Directly from the 'Horses' Mouths* [Online]. Available: (link in title)
44. Mar, Countess of. 2004, *House of Lords Debate* [Online], Available: (link in title)
45. Marshall, Eileen & Williams, Margaret. 2006a, *Some of the abnormalities that have been demonstrated in ME/CFS* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
46. Marshall, Eileen & Williams, Margaret. 2006b, *Inquest implications* [Online], Available: <http://www.hfme.org/wmarwillinquest.htm>
47. Marshall, Eileen & Williams, Margaret. 2006c, *Myalgic Encephalomyelitis exists: True or false?* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
48. Marshall, Eileen & Williams, Margaret. 2005a, *Problems and solutions?* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
49. Marshall, Eileen & Williams, Margaret. 2005b, *Proof positive? Evidence of the deliberate creation via social constructionism of "psychosocial" illness by cult indoctrination of State agencies, and the impact of this on social and welfare policy* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
50. Marshall, Eileen & Williams, Margaret. 2005c, *To set the record straight about Ean Proctor from the Isle of Man* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
51. Marshall, Eileen & Williams, Margaret. 2005d, *Profits before Patients?* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
52. Marshall, Eileen & Williams, Margaret. 2004a, *A note on the term Myalgic Encephalomyelitis* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
53. Marshall, Eileen & Williams, Margaret. 2004b, *Transparency in government* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
54. McLaughlin, Jill, 2004, *"Information on Myalgic Encephalomyelitis (M.E.)/Chronic Fatigue Syndrome (CFS)"* [Online], Available: <http://www.hfme.org/wfauthors.htm>
55. Michell, Lynn 2003, *Shattered: Life with ME*, Thorsons Publishers, London
56. Munson, Peggy (ed) 2000, *Stricken; Voices from the Hidden Epidemic of Chronic Fatigue Syndrome*, The Haworth Press, New York
57. Peckerman A, LaManca JJ, Dahl KA, Chemitiganti R, Qureishi B, Natelson BH. 2003, *Abnormal Impedance Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome*, *The American Journal of the Medical Sciences*: 2003;326:(2):55-60)

58. Ramsay, A. 1988, *Myalgic Encephalomyelitis and Postviral Fatigue States: The saga of Royal Free Disease*, Gower Medical Publishing, London.
59. Ramsay, Melvin A. 1989, ME Association Newsletter, Winter 1989: pp. 20-21.
60. Ramsay, Melvin A. n.d., *The Myalgic Encephalomyelitis syndrome* [Online], Available: <http://www.hfme.org/wramsay.htm>
61. Ramsay, Melvin A. 1986, *MYALGIC ENCEPHALOMYELITIS : A Baffling Syndrome With a Tragic Aftermath.* [Online], Available: <http://www.hfme.org/wramsay.htm>
62. Richardson, J. 1999, *Myalgic Encephalomyelitis: Guidelines for doctors* [Online], Available: <http://www.hfme.org/wrichardson.htm>
63. Richardson, J. n.d., 'M.E., *The Epidemiological and Clinical Observations of a Rural Practitioner,*' *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Hyde, Byron M.D. (ed) The Nightingale Foundation, Ottawa, pp. 85-94.
64. Ryll, Erich D. 1994, INFECTIOUS VENULITIS, CHRONIC FATIGUE SYNDROME, MYALGIC ENCEPHALOMYELITIS, [Online], Available: <http://www.geocities.com/tcjrme/recommend23.html>
65. San Diego Chronic Diseases, [Online], Available: <http://www.sandiegocd.org/index.html>
66. The Committee for Justice and Recognition of Myalgic Encephalomyelitis 2007, [Online], Available: <http://www.geocities.com/tcjrme/>
67. The 25% M.E. Group. 2004, *SEVERELY AFFECTED ME (MYALGIC ENCEPHALOMYELITIS) ANALYSIS REPORT ON QUESTIONNAIRE* [Online]. Available: (link in title)
68. The 25% M.E. Group (comments by Greg Crowhurst) 2005, *Submission To The Parliamentary Inquiry Into Progress In The Scientific Research Of M.E. By The 25% ME Group*, [Online]. Available: <http://www.hfme.org/w25group.htm>
69. The ME Society of America website 2007, [Online], Available: <http://www.cfids-cab.org/MESA/framework.html>
70. Verillo, Erica F & Gellman, Lauren M 1997, *CFIDS - A Treatment Guide*, St. Martin's Griffin, New York
71. Walker, Martin J. 2003, *SKEWED: Psychiatric Hegemony and the Manufacture of Mental Illness in Multiple Chemical Sensitivity, Gulf War Syndrome, Myalgic Encephalomyelitis and Chronic Fatigue Syndrome*, Slingshot Publications, London.
72. Web M.D. website 2009, [Online], Available: <http://www.webmd.com>
73. Williams, Margaret 2004, *Critical considerations*, [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
74. Williams, Margaret 2003, *Quotations from "SOMATIC MEDICINE ABUSES PSYCHIATRY - AND NEGLECTS CAUSAL RESEARCH" by Per Dalen* [Online], Available: <http://www.hfme.org/wmarshallandwilliams.htm>
75. Quintero, Sezar 2002, *Sophisticated Investigation, or How to Disguise a Disease*, [Online], Available: <http://www.geocities.com/sezar99q/>

Before reading any of the above links to research/advocacy information, please be aware of the following facts:

1. Myalgic Encephalomyelitis (M.E.) and 'Chronic Fatigue Syndrome'(CFS) are not synonymous terms. The overwhelming majority of research on 'CFS' or 'CFIDS' or 'ME/CFS' or 'CFS/ME' or 'ICD-CFS' does not involve M.E. patients and is not relevant in any way to M.E. patients.

If the M.E. community was to reject all 'CFS' labelled research as 'only relating to 'CFS' patients' (including research which describes those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that 'CFS' is just a 'watered down' definition of M.E. and that M.E. and 'CFS' are virtually the same thing and share many characteristics.

A very small number of 'CFS' studies/articles and books refer in part to people with M.E., but it may not always be clear which parts refer to M.E. The [A warning on 'CFS' and 'ME/CFS' research and advocacy](#) paper is recommended reading and includes a checklist to help readers assess the relevance of individual 'CFS' studies (etc.) to M.E. (if any) and explains some of the problems with this heterogeneous and skewed research.

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. The bogus, financially-motivated disease category of 'CFS' must be abandoned.

The research referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology;. other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as 'CFS,' 'ME/CFS,' 'CFS/ME,' 'CFIDS' or Myalgic 'Encephalopathy' and also include a significant amount of misinformation. Before reading this research it is also essential that the reader be aware of the most commonly used 'CFS' propaganda, as explained in [A warning on 'CFS' and 'ME/CFS' research and advocacy](#) and in more detail in [Putting research and articles on M.E. into context.](#)

Note that this list may contain some references which are not directly referenced in this paper (as this list also serves as a reference list for several other papers).

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Disclaimer

HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site or readers of any of the HFME books. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

Relevant quotes

‘The problem with fatigue is that it is neither specific, definable nor scientifically measurable. Fatigue is both a normal and a pathological feature of every day life. Every normal person gets fatigued. Fatigue is a common feature of much major psychiatric disease and major medical disease. Since fatigue is such an integral part of many illnesses, by calling fatigue the primary characteristic, the authors necessitated the elimination of hundreds of other diseases. To truly follow the criteria set out by the CDC definition probably makes 'CFS' the most expensive illness to investigate of any known disease. Fatigue is not an object, it is simply a modifier in search of a noun. Also, taking fatigue as the flagship symptom of a disease not only bestows the disease with a certain Rip Van Winkle humour, but it removes the urgency of the fact that the majority of M.E. symptoms are in effect CNS symptoms. M.E. represents a major attack on the CNS by the chronic effects of a viral infection.’

BYRON HYDE MD IN ‘THE CLINICAL AND SCIENTIFIC BASIS OF M.E. P 11-12

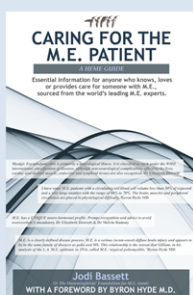
‘Western newspapers and magazines are packed with trivia, television news is concealing the reality of what is happening... and investigative journalism has virtually died a death. [But] what is the point of democracy if you keep the citizens in a state of semi-ignorance?’

VETERAN ACTIVIST, PROTESTER AND AUTHOR TARIQ ALI

‘Despite the claims of some psychiatrists, it is not true that there is no evidence of inflammation of the brain and spinal cord in M.E.; there is, but these psychiatrists ignore or deny that evidence. It is true that there is no evidence of inflammation of the brain or spinal cord in states of chronic fatigue or ‘tiredness.’

THE TERMINOLOGY OF M.E. & CFS BY PROFESSOR MALCOLM HOOPER

‘There is a principle which is a bar against all information, which is proof against all argument, and which cannot fail to keep man in everlasting ignorance. That principle is condemnation without investigation.’ WILLIAM PALEY (1743-1805)



This paper is included in the new *Caring for the M.E. Patient* book by Jodi Bassett.

The book also includes a Foreword by the world's most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the *HFME Books* page on www.hfme.org

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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UPDATED JUNE 2011. TAKEN FROM WWW.HFME.ORG



- Myalgic Encephalomyelitis (M.E.) is a disabling neurological disease that is very similar to Multiple Sclerosis (M.S.) and Poliomyelitis. Earlier names for M.E. were 'atypical Multiple Sclerosis' and 'atypical Polio.'
- M.E. is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This damage is an essential part of 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, tis = 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. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.
- M.E. 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.
- M.E. 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.
- M.E. can be more disabling than M.S. or Polio, and many other serious diseases. M.E. is one of the most disabling diseases that exists. 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 M.E. 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 (e.g. 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.*
- M.E. 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 (e.g. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- M.E. is a long-term/lifelong neurological disease that affects more than one 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.