Putting research and articles on M.E. into context

Taken from www.hfme.org

Most people would readily accept that when politicians talk about subjects that they have an involvement with that they can often be quite biased in their approach and very often much of what is said is more concerned with protecting their own vested interests rather than just being a simple explanation of the facts. In contrast to this, the fields of medicine and science are usually seen as fairly 'black and white' and therefore immune from such manipulations. The unfortunate reality however is that just like any other field where many billions of dollars are at stake, these areas are as open as any other to clever and unethical manipulation by those with something to gain either financially or politically by skewing and misrepresenting the facts in a particular way.

Research into Myalgic Encephalomyelitis (M.E.) is a prime example of this. Because of the enormous amounts of money at stake, research into M.E. is not a politically neutral field. Very often the language used and many of the claims made about the illness in supposedly scientific studies should not be taken at face value or accepted as being based on an objective look at the evidence.

For example, it has recently been uncovered that some of the worlds most influential and prolific authors of studies (and *many* media reports and governmental advisory papers) which have supposedly showed the illness to be a purely psychiatric or 'behavioural' condition have been hiding long-held ties and loyalties to the powerful health insurance industry. This is an industry which stands to lose literally billions of dollars (and possibly even face financial collapse) if M.E. is ever fully formally recognised as the severely debilitating infectious organic neurological disease that it is. (Reference) (Reference)

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 on going "fatigue", a symptom so universal that any insurance claim based on "tiredness" could be expediently denied. The new case definition

> bore little relation to M.E.: objections were raised by experienced international clinicians and medical scientists, but all objections were ignored… To the serious disadvantage of patients, these psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to government 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.

This is why the charade that M.E. could be a psychiatric or behavioural disorder or even a 'belief system' continues; not because there is good scientific evidence (or any evidence) for it, or because the evidence proving organic causes and effects is lacking – but because such a view is so *financially and politically* convenient and profitable on such a large scale to a number of powerful corporations and government departments with vested interests. (Reference). (See: Who benefits from 'CFS' and 'ME/CFS'?)

There simply is no legitimate and scientifically motivated debate about whether or not M.E. is a 'real' illness or not, or whether or not it is 'behavioural' or has a biological basis. The psychological or behavioural theories of M.E. are no more scientifically viable than are the theories of a 'flat earth.' They are pure fiction. Strong evidence of the biological basis for the illness has existed since the 1930s and 1950s and more than 1000 good articles now support the basic premise of M.E. as a debilitating organic neurological illness. This is not simply theory, but is based upon an enormous body of clinical information. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis. M.E. is not 'medically unexplained' (or 'unexplainable'). Many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research articles. These are well-documented, scientifically sound explanations for why patients are often bedridden and unable to maintain an upright posture. (Reference)

Substantial evidence also exists to show that it is simply not possible that somatisation, secondary gain, malingering, aberrant illness beliefs, too much focus on normal bodily sensations, irrational fear of exercise leading to deconditioning, being rich and white, being poor and from an ethnic minority,

being lazy and unwilling to work, being too highly driven and perfectionistic and working too hard, faulty thought processes, lack of motivation, long-term stress, acute stress, abuse in childhood, a genetic inability to deal with normal levels of stress, inadequate coping strategies and contagious sociological hysteria – or any or the other ridiculous and often contradictory 'theories' put forward by these vested interest groups – play a role in causing or perpetuating authentic M.E. (Reference)

The reality is that anyone, whether medically qualified or not, who looks at the worldwide published medical evidence on M.E. could not fail to recognise that the psychological or psychiatric theories could not possibly explain the many different and profound physical abnormalities seen in M.E. (nor the many other characteristics of the disease which are not consistent with psychological or behavioural illness). There are only two ways that a person could reach a different conclusion:

1. Bias due to vested political or financial (or other) interests
2. Lack of access to a truly representative selection of the evidence (ie. an individual has only availed themselves of the pseudo-science provided by financial stakeholders and not a representative selection (or indeed *any*) of the legitimate and unbiased science before forming an opinion on the illness.)

The disease category 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of Myalgic Encephalomyelitis by allying it with various unrelated psychiatric fatigue states and fatigue syndromes (etc). Despite the fact that the new name and definition of CFS were created in a response to an outbreak of what was unmistakably M.E., this new name and definition did not describe the known signs, symptoms, history or pathology of M.E. It described a disease process which did not, and could not exist. There are now more than 9 different CFS definitions. None of them describes of defines Myalgic Encephalomyelitis. All each of these definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue.

Under the cover of 'CFS' these vested interest groups have assiduously attempted to obliterate recorded medical history of Myalgic Encephalomyelitis; even though the existing evidence and studies were published in prestigious peer-reviewed journals and span over 70 years The only way forward for M.E. patients and all those patients misdiagnosed with 'CFS' (both of which are denied appropriate support, diagnosis and treatment) is that the disease category of 'CFS' must be abandoned completely (Reference).

Not all those involved with 'CFS' have vested financial and political interests however, yet these non-vested-interest groups still also produce similarly flawed, psychiatrically biased and 'fatigue' based information. Unfortunately these other groups have been unduly swayed and manipulated to varying extents by the enormous amount of superficially legitimate information widely disseminated by such powerful vested groups and individuals. Some researchers have seemingly been taken in entirely by such scientifically unsupportable theories, as have the large majority of the world's journalists and politicians (albeit with some notable exceptions). Even some of the best research on the illness is shrouded in heavy usage of misleading and propagandising language and false statements which often bizarrely contradict the harsh realities uncovered in the studies themselves.

(True M.E. experts such as Dr. Elizabeth Dowsett, Dr Byron Hyde, and the late Dr Melvin Ramsay. (and many others) however have easily been able to see through the 'CFS' nonsense and have continued to study authentic M.E. and to add to what we know about M.E., without tainting their work with this propaganda. Not everyone was taken in by the 'CFS' insurance scam thankfully! Legitimate unbiased M.E. experts and researchers do exist, and their numbers continue to grow, albeit much more slowly than is needed.)

Because of the politics involved in every aspect of M.E., the vast majority (an estimated 95%, at least) of what is written about the illness has little or no relationship with the scientific reality of M.E. In fact, it is not uncommon to read widely redistributed articles made up *entirely* of such mistruths and propaganda! For this reason it is vital that all writings on M.E. are put into context.

- To read more information on this topic see: Who benefits from 'CFS' and 'ME/CFS'? plus What is ME? What is CFS? Information for Clinicians & Lawyers and also Smoke and mirrors, The misdiagnosis of CFS and What is M.E.? (on this site), 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 and The Complexities of Diagnosis and The Nightingale Definition of M.E.
- See also: Worldwide Epidemic, Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis (174 pages), Research into ME - 1988-1998 Too much PHILOSPHY and too little BASIC SCIENCE!

A Rose By Any Other Name, and Redefinitions of ME. Many more relevant papers are also available in the Research and Articles section.

Before reading the research/advocacy information on this site, please be aware of the following facts:

1. Myalgic Encephalomyelitis and 'Chronic Fatigue Syndrome' 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 were to reject all 'CFS' labelled research as 'only relating to 'CFS' patients' (including research which describes those abnormalities or 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.

2. 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 the sections below.

- For 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'

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

"…the primary symptom is severe fatigue…"

The defining feature of Myalgic Encephalomyelitis is not fatigue (or tiredness or a lack of 'energy' or 'poor stamina'). M.E. is characterised primarily by viral damage to the central nervous system (the brain) which results in dysfunctions and damage to many of the body's vital systems and a loss of normal internal homeostasis (Reference). The 'f' word was selected entirely for what it could achieve politically: it was never intended to be a genuine medical description of the symptomatology of this illness (Reference).

Myalgic Encephalomyelitis 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. To suggest such a thing 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., nor even an essential symptom of M.E.

'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. (and is 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 (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, breathing difficulties, and so on. 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 often are so ill that they feel they are about to die. People with M.E. would give *anything* to instead only be severely 'fatigued' or tired all the time.

Fatigue or 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'

Some push the concept of 'fatigue' entirely as a tool to try to incorrectly place M.E. into the realm of the psychiatric, while others use it in a more complex way: if you asked the author to explain what was meant by the word they would describe something that bore no relation to any known definition of fatigue – but yet they use the word anyway simply because others with vested interests so often do so, causing obvious confusion. Understanding of this illness would be greatly advanced if this misleading and confusing practice were to be immediately stopped by all legitimate researchers and advocates. As The M.E. Society of America explain "Symptoms can be described in specific, accurate terminology without reference to broad or demeaning term[s] such as "fatigue" or "poor stamina." (Reference).

- See ME is not fatigue, Testing for Myalgic Encephalomyelitis, The Nightingale Definition of M.E., Fatigue Schmatigue, and M.E. is not defined by 'fatigue' for more information.

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

All three of these statements are false. There are in fact a variety of physical signs in M.E. patients as well as a series of tests which can be done to confirm a suspected M.E. diagnosis and symptoms may indeed be clearly articulated (Reference). Once a physician has some experience with the illness, M.E. is not at all a difficult illness to diagnose and non fatigue-based definitions such as the Nightingale definition of M.E. now make diagnosis easier than ever before; even for those with no experience with the illness. The illness may also be diagnosed relatively early in the course of the disease (eg. after just 2 weeks). Claims that the illness can only be diagnosed after 6 months have passed are

absurd and not based on any observation relevant to actual M.E. patients (along with virtually the entirety of each of the different 'CFS' definitions).

Whilst various 'fatiguing conditions' with a variety of different etiologies may be made up of vague and mild 'everyday' type symptoms, have no physical signs and no tests which can aid diagnosis, M.E. is a distinct neurological illness with a distinct list of symptoms, physical signs and diagnostic (and other) tests. It bears no relationship with such unrelated, vague and hard to diagnose 'fatiguing conditions' or with 'CFS.'

- See Testing for Myalgic Encephalomyelitis and The Nightingale Definition of M.E. for more information.

"…it is an illness which can only be diagnosed by exclusion…."
It is true that the many different definitions of 'CFS' which have been created are merely diagnoses of exclusion. But these definitions do not define M.E. (nor any other distinct disease) M.E. is a distinct illness which can be easily diagnosed by careful analysis of a patients symptomatology, looking for some of the physical signs of M.E. and also performing a series of tests which can help to confirm the diagnosis. The illness has several unique features and a unique neuro-hormonal profile. M.E. is NOT a diagnosis of exclusion as 'CFS' is.

- See Testing for Myalgic Encephalomyelitis, The misdiagnosis of CFS and The Nightingale Definition of M.E. for more information.

"….there are no lab tests…"
The fact that there is as yet no *single* test which can diagnose M.E. is often written in a way which implies that there are NO lab tests anywhere which have ever shown anything at all being organically abnormal or damaged in any M.E. patients. This is simply an absurd claim. The truth is that while it is true there is no SINGLE test which can confirm a suspected M.E. diagnosis in 100% of cases, there are a SERIES of tests which can (Reference). Furthermore, *hundreds* of different studies (some dating back to the 1950s or earlier) have found measurable and in some cases extremely severe abnormalities in many different bodily systems of M.E. patients (Reference). All tests will only come back normal – as with all illnesses – if completely the wrong tests are done, or if those tested do not in fact have Myalgic Encephalomyelitis in the first place.

(This is also why many researchers find different or inconsistent results – because they use different and inconsistent patient groups, see: The Definitions of ME, The misdiagnosis of CFS and Smoke and mirrors for more information. In addition, the loose and over-inclusive diagnostic criteria themselves (along with a politically motivated lack of funding) are likely also largely responsible for that lack of a single diagnostic test).

Despite all the freely available evidence that so easily disproves this misleading statement it has been amazingly successful at covering up the truth. It seems to stop many from doing even the most basic research before announcing their own findings. Dozens (if not hundreds) of individual studies over the last 20 years each claim to be the very first to have 'finally' found objective proof of illness in M.E. patients. The funny thing is that they are all false claims as objective evidence for the organic basis of M.E. has existed since the 1930s and 1950s!

It is true however that there are no tests which can be used to diagnose or prove the existence of 'CFS' but M.E. and 'CFS' are not at all the same thing.

Some of the series of tests which can (in combination) help to confirm a M.E. diagnosis include:

- SPECT and xenon SPECT scans of the brain
- MRI and PET scans of the brain
- Neurological examination and the Romberg or tandem Romberg test
- Various tests of the immune system
- Insulin levels and glucose tolerance tests
- 24 hour Holter monitor
- Tilt table examination, exercise testing and chemical stress tests, and
- Physical exam

- See Testing for Myalgic Encephalomyelitis, The misdiagnosis of CFS and The Nightingale Definition of M.E. for more information. See also 'The saga of Royal Free Disease' by Melvin Ramsay and The Clinical and Scientific Basis of Myalgic Encephalomyelitis for more information. See also Defining M.E., M.E: The Medical Facts
- See also: Worldwide Epidemic, and Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis (174 pages)

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

Statements which imply that there has been generous funding and extensive genuine research into the biomedical facts of the illness yet that there have been only scant results to be found are utterly divorced from reality as indeed the exact opposite is true. M.E. is a comparable illness physically to Multiple Sclerosis and yet 'CFS' research receives *less than 10%* of the level of government funding that MS does. A recent article explained that 'Breast cancer is diagnosed in 26 women per 100,000 and receive $716 million dollars in government research funds; lung cancer is diagnosed in 63 women per 100,000 and receives $300 million in government research funds; HIV is diagnosed in 125 women per 100,000 and receives $2921 million in government research funds; and CFS is diagnosed in anywhere from 300-540 women per 100,000 and receives $6 million in government research funds. Research funding for CFS [in the US] is about 107th out of 110 diseases funded (Reference).

To make matters worse, much of even that small amount given to 'CFS' research is wasted doing vague studies on 'fatigue' that have absolutely no relevance to M.E. patients (or indeed to any other distinct patient group). M.E. is in reality one of the most poorly funded illness today; considering its brutal severity and the vast numbers of patients involved, this is a worldwide disgrace. As The M.E. Society of America explains: "It is miraculous that so much good research turned up given the [many drawbacks], which speaks to the seriousness of the disease" (Reference).

- Governments worldwide currently spend 0$ a year on M.E. research. To make a donation to M.E. research see: Donations.

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

The 'biopsychosocial' theory is just a new way of pushing the same old flawed and disproven psychiatric theories yet again, under the guise of pseudo-legitimate science. Again, those who advocate this theory are also studying patients with 'fatigue' and not those with actual M.E. M.E. is no more a uniquely biopsychosocial illness than Multiple Sclerosis, Parkinson's or any other organic neurological disease. M.E. is also no more 'mysterious' or 'baffling' than either of these illnesses. As patient advocates Margaret Williams and Eileen Marshall explain:

> Unless the disease itself is robustly investigated and understood -- and ultimately treated -- no amount of psychosocial 'management' will have worthwhile or lasting effects upon the hapless sufferer trying to cope without

medical support with serious and destructive organic pathology. If the biopsychosocial approach worked in cases of authentic ME, patients would be clamouring for it, not refusing it, but it clearly does not work in ME and graded exercise may even be life-threatening. (Reference)

As The M.E. Society of America writes: "Unlike somatisation disorder, M.E. is not "medically unexplained." M.E. is a disease which, like lupus, has no single marker. Many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research. These are well-documented, scientifically sound explanations for why patients are often bedridden and unable to maintain an upright posture." (Reference).

- The CBT and GET database is a comprehensive guide to the use of CBT and GET on patients with Myalgic Encephalomyelitis. It contains excerpts and links to literally hundreds of articles and research studies which expose the lack of scientific legitimacy (and the hidden financial and political motivations) underlying the 'behavioural' or 'biopsychosocial' paradigm of M.E. and the use of these inappropriate interventions. The effects of CBT and GET on patients with Myalgic Encephalomyelitis looks at the physical effects of CBT (psychotherapy) and GET (graded exercise) on patients with M.E.
- See also What is ME? What is CFS? Information for Clinicians & Lawyers and M.E: The Medical Facts and the excellent book: The Clinical and Scientific Basis of Myalgic Encephalomyelitis

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

It is often assumed that all patients with M.E. suffer with significant levels of anxiety and depression (Reference). Levels of depression reported in M.E. populations vary, but the figure is nowhere near even 50%, let alone 100%. Studies have shown the depression rates in M.E. patients to be comparable to those of Multiple Sclerosis or Rheumatoid Arthritis patients (Reference). Many researchers compound this error by also writing as if some level of psychiatric or 'behavioural' causation of the illness has also been legitimately proven. The key word here is 'legitimately.' Therapies based upon these flawed theories are also often written about as if they have been legitimately proven to be effective (CBT and GET for example). The key word here is again, 'legitimately.'

Despite popular opinion, there is in fact *no evidence whatsoever* which exists to show that Myalgic Encephalomyelitis can be caused or perpetuated by psychiatric or behavioural problems; nor that therapies such as CBT or GET are

appropriate, safe or useful in treating M.E. patients. The studies which support these theories and the use of these therapies have been conducted not on people with M.E. but instead on patients with an entirely unrelated health problem – the symptom of fatigue.

Studies involving people suffering with the symptom of 'fatigue' have no more relevance to authentic M.E. sufferers than they do to those with MS, or diabetes, or any other illness. The results of studies on one patient group simply cannot be used to determine the aetiology, treatment and prognosis of a second *unrelated* patient group. This is unscientific and violates basic human rights. People with M.E. have suffered greatly because of this nonsensical approach and some sufferers have died from these inappropriate interventions (and from a lack of basic appropriate medical care).

- This is a key issue, or perhaps the issue facing M.E. advocates and researchers today and as such many articles on this topic are available. To read more information on this topic see: Smoke and mirrors, The misdiagnosis of CFS and What is M.E.? (on this site), M.E. Fatalities, 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 and The Complexities of Diagnosis and The Nightingale Definition of M.E. Research into ME - 1988-1998 Too much PHILOSPHY and too little BASIC SCIENCE! A Rose By Any Other Name, and Redefinitions of ME.
- Many more relevant papers are also available in the Research and Articles section. See also What is ME? What is CFS? Information for Clinicians & Lawyers and also What is M.E.? (on this site), Worldwide Epidemic, Research into ME - 1988-1998 Too much PHILOSPHY and too little BASIC SCIENCE! A Rose By Any Other Name, and Redefinitions of ME. Many more papers are also available throughout the Research and Articles section.

"…these CFS patients showed…"

Most studies which use the name CFS are not in any way concerned with the illness known since 1956 as Myalgic Encephalomyelitis. The two terms are NOT synonymous. The Oxford criteria for CFS for example, only requires that a person experience the symptom of fatigue for the diagnosis to be made. Therefore, when 'CFS' studies are done using the Oxford criteria, what is being studied are merely patients with 'fatigue', and not M.E. (Obviously there is a basic misunderstanding of the meaning of the word 'syndrome').

There are more than nine different definitions of CFS. The Fukuda and Australian CFS definitions are very similar to the Oxford definition. None of them describes M.E. or any other distinct illness. It is so important that the results from studies using these broad and inclusive and fatigue-based definitions are not thought to apply to patients with M.E., or with M.E. equivalent CFS (as per the World Health Organisation's ICD Classification). Despite the confusing sharing of the name 'CFS,' such groups are apples and oranges. As The M.E. Society of America write, 'We must understand that disease entities are facts and phenomena, while names and case definitions are mere human constructs. Some constructs are more accurate than others. Some select a different population than others.'

As M.E. expert Dr Byron Hyde explains:

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

All a diagnosis of 'CFS' actually means is that the patient has a gradual onset fatigue syndrome which is usually due to a *missed major disease*. As Dr Byron Hyde explains, the patient has:

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

The results of such studies on fatigued persons (and/or people with all sorts of other illnesses) should never be used to determine treatment of M.E. patients as tragically is what happens so often now. This leaves people with M.E. not only

without the new treatments which legitimate research would bring but often forced to undergo all sorts of useless and even severely harmful treatments in their stead (such as psychotherapy, antidepressants and exercise programs).

Contrary to popular belief, Myalgic Encephalomyelitis is a distinct, recognisable entity that can be diagnosed relatively early in the course of the disease, providing the physician has some experience with the illness.

- See Testing for Myalgic Encephalomyelitis, The misdiagnosis of CFS and The Nightingale Definition of M.E. for more information. See also What is ME? What is CFS? Information for Clinicians & Lawyers and M.E: The Medical Facts and the excellent book: The Clinical and Scientific Basis of Myalgic Encephalomyelitis See also ME and CFS, the Definitions, A Rose By Any Other Name, and Redefinitions of ME. for more information, as well as the Definitions of M.E. section on this site.

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

It should always be kept in mind when reading through research into M.E. that the patients being studied are almost exclusively those in the mild – to *possibly moderate* in some cases – range of severity. A recent study by MERGE showed that **more than 99%** of all studies on M.E. involved such patients and that even in those few studies which did claim to be studying severe M.E. patients, the patients were still a long way from being the most severely ill (Reference).

For example, two recent studies looked at reduced blood volume in M.E. patients. The first study used the standard revised CDC criteria which has been shown to select for mildly ill (and non-M.E.) patients (Reference), while the second study conducted by an experienced M.E. specialist (David S. Bell, M.D) and was conducted using some of his more severely ill patients. The first study found 'an insignificant trend towards low blood volume of 9%.' The second study found that 'In some individuals this abnormality was strikingly severe. Patient #15, for example, had an RBC mass of 12.9 mL/Kg, which is 46% of the expected normal, and a total blood volume of 35.8 mL/Kg, which represents 49.7% of the expected normal value.' (Reference) There are many other examples of this: reports of only very mild hypocorticolism (in mildly ill patients) while some severely ill patients have cortisol levels which are dangerously low and require urgent medical attention. Many studies report only mild intellectual disability in M.E. patients while those who have studied the severely ill describe over and over again patients who are unable to read or write, speak or understand speech or even to recognise close family members.

Some patients who used to hold professional jobs requiring university degrees pre-illness, now almost meet the legal definition of 'idiocy' – this is hardly a 'mild intellectual disability.' The list goes on.

The 'mild' abnormalities found in some studies may mean that whatever is being tested for is not relevant to the pathology of M.E., but they may also merely be indicative of the fact that mildly ill patients will – unsurprisingly – often show only mild abnormalities. It is important in the future that the severity of each patient's illness is recorded in each study, and that more studies are done using severely ill sufferers.

- See The severity of M.E. and for more information, as well as the Definitions of M.E. section on this site.

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

The terms 'CFS' and 'chronic fatigue,' despite the many useless and fatigue-based definitions of CFS, CANNOT be used interchangeably. It is one thing to misunderstand the meaning of a word, but it is another entirely to write as if a word had no meaning at all. Far from the word 'syndrome' having no meaning, it is in fact quite a powerful word – the use of the term completely changes the meaning of the words preceding it. In medicine, the term syndrome means 'a collection or group of symptoms.' Thus you simply cannot have a syndrome which has only one symptom or characteristic.

For example, recent studies have shown that (among other measures) avoiding both second-hand cigarette smoke and sleeping while lying on the stomach greatly reduce the incidence of sudden infant death SYNDROME (or SIDS). Such measures however, are useless in preventing sudden infant deaths from other causes such as drowning, choking or car accidents. The use of the word SYNDROME completely changes what is being discussed, it makes it clear that it is **a specific type** of sudden infant death with many other associated signs and symptoms which is being discussed and not just sudden infant deaths in general. Clearly the word SYNDROME changes the meaning completely. Chronic fatigue, 'CFS' and M.E. are not the same.

- People with **chronic fatigue** may be tired because of cancer, Multiple Sclerosis, vitamin deficiency, a sleep disorder, depression or a large number of other reasons. Fatigue or chronic fatigue is a symptom of many illnesses. Up to 20% of the population may currently suffer from some form of chronic fatigue.

- **Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.
- **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

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

It makes what is being written utterly nonsensical if the terms 'chronic fatigue' and 'chronic fatigue SYNDROME' and 'Myalgic Encephalomyelitis' are used interchangeably. This very common error is so disturbing because it originates not from the widespread dissemination of propaganda on M.E., but is instead due at least in part to a surprising lack of the most basic understanding of language in today's supposedly well educated journalists and researchers.

- See Smoke and mirrors and The misdiagnosis of CFS for more information. See also the Definitions of M.E. section on this site, What is ME? What is CFS? Information for Clinicians & Lawyers and also What is M.E.? (on this site) A Rose By Any Other Name, and Redefinitions of ME. Many more

papers are available on this topic throughout the Research and Articles section.

"…cancer patients also experience severe fatigue, so…."
Many studies which misrepresent the main feature of the illness as 'fatigue' then go on to compound this error by comparing and discussing the legitimate fatigue and tiredness experienced by patients with many other illnesses as if the two patient groups were experiencing the same symptom. This is not the case as the word fatigue is being misused in being applied to M.E. patients. The main symptom of M.E. is not fatigue and so it is a case of apples being compared with oranges yet again. Studies on the level of fatigue in other illnesses and how this can be improved have absolutely no relevance to the symptomatology or pathology of M.E., and vice versa.

OMISSIONS: Sometimes it is what studies and other writings on M.E. *don't* say that is every bit as misleading as the propaganda and other false and misleading statements which are used. One can only imagine that such facts are omitted simply because each of them alone so easily disproves the psychological or 'behavioural' theories of M.E.. They include (but are not limited to):

Mentions of the deaths from M.E. are almost always omitted, as is the true severity of the illness and the actual recovery rates. Many sufferers are extremely ill and housebound, wheelchair-bound or bedbound for many years with M.E. yet the effects of the illness are usually portrayed as being uniformly 'mild.' (Even moderately ill sufferers are rarely described let alone the severe). As The M.E. Society of America writes: "Many cases of M.E. are progressive and degenerative (around 30% of cases), and some have led to complications that were terminal. (Reference). The true rates of recovery from M.E. are also usually omitted (recovery rates are often vastly overestimated, or even claimed to be 100%, which unfortunately does not reflect reality.)

- See M.E. Fatalities, THE LATE EFFECTS OF ME and the excellent book: The Clinical and Scientific Basis of Myalgic Encephalomyelitis and The severity of M.E. for more information.

The more than 60 recorded outbreaks of M.E. worldwide since 1934 are often (almost always) completely ignored and omitted. (Reference).

- For more information see: The outbreaks (and infectious nature) of M.E., (this page contains links to many different relevant books and articles).

The long history of Myalgic Encephalomyelitis research which goes back to 1934 is often omitted – the illness did not just suddenly appear in the 1980s for the first time as many articles falsely claim.

The existence of an enormous amount of solid and credible research proving organic and severe illness in M.E. patients going back to the 1930s and 1950s is also often omitted completely. (Reference)

- See the excellent book by Dr Byron Hyde et al: The Clinical and Scientific Basis of Myalgic Encephalomyelitis for more information as well as What is ME? What is CFS? Information for Clinicians & Lawyers, What is M.E.? (on this site), Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis (174 pages) and Worldwide Epidemic. Many more papers are available on this topic throughout the Research and Articles section.

The real constellation of symptoms is rarely mentioned. Many articles list only some of the very minor symptoms as if these are what characterise the illness – symptoms such as a sore throat, headaches and joint aches (and the ubiquitous 'fatigue') while omitting many more serious and common symptoms such as seizures, paralysis, neurally mediated hypotension, tachycardia and other severe cardiac abnormalities, severe cognitive deficits and many more.

The damage to the central nervous system which truly characterises the illness and causes a loss of homeostasis and problems with dealing with certain levels of physical activity, cognitive exertion, orthostatic stress, sensory stress or infectious stress are likewise rarely even mentioned. This gives a false sense of the realities of the illness as such descriptions bear little or no relationship to the type and severity of illness patients are actually experiencing. Individual symptoms of Myalgic Encephalomyelitis 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, opthalmoplegia, 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 (eg. facial agnosia). There is often a marked loss in verbal and performance intelligence quotient (IQ) in 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 also the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. In other words, the pattern of symptom exacerbations, relapses and of 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 brain (the central nervous system) this characteristic is one of the defining features of the illness which 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 (and so on) in Myalgic Encephalomyelitis include:

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 post-M.E.
B. People with M.E. are limited in how physically active they can be but they are also limited in similar way 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 this causes 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 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: a gradual (or sudden) increase in activity levels beyond a patient's individual limits can only cause relapse, disease progression or death in patients with M.E.
I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused 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. 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 the very severely affected.

- See Testing for Myalgic Encephalomyelitis, The misdiagnosis of CFS and The Nightingale Definition of M.E. for more information, plus The Comprehensive M.E. Symptom List

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Other myths about M.E. commonly presented as 'fact' include the following:

1. MYTH: M.E. is a new illness that appeared for the first time in the 1980s
2. MYTH: M.E. does not occur in outbreaks or epidemics

3. MYTH: M.E. is an illness whose primary and defining feature is ‘chronic fatigue.’
4. MYTH: Myalgic Encephalomyelitis and ‘CFS’ are synonymous terms
5. MYTH: People suffering with chronic fatigue have mild M.E.
6. MYTH: All studies or articles which use the terms CFS (or ME/CFS, CFS/ME, CFIDS or Myalgic Encephalopathy) are discussing the same patient group
7. MYTH: The 8 symptoms – along with fatigue – listed in the CDC’s 1994 Fukada CFS diagnostic criteria (short-term memory or concentration problems, sore throat, tender cervical or axillary lymph nodes, multi-joint pain, muscle pain, headaches, non-refreshing sleep and/or post-exertional malaise) are the symptoms which define M.E. Fitting the Fukada criteria for CFS, or any of the other CFS definitions, means that a person has Myalgic Encephalomyelitis

8. MYTH: Fibromyalgia and M.E. are basically (or exactly) the same illness: fatigue is the worst symptom of M.E. and in Fibromyalgia the worst symptom is always pain and that's really the only way you can tell which one you have. M.E. is also basically (or exactly) the same illness as Lyme disease, Multiple Chemical Sensitivity Syndrome and Gulf War Syndrome etc.

9. MYTH: M.E. is a mild illness from which every person will eventually completely recover and is never progressive or fatal

10. MYTH: M.E. has been scientifically proven to be caused by psychological factors. M.E. is a 'mysterious' illness with many 'medically unexplained' symptoms and seems to ‘transcend the boundaries between the body and the mind’ like no other. No research exists which shows that M.E. has a physical or organic basis

11. MYTH: M.E. is consequent from an organic (viral) trigger but the illness is short lived unless there are psychological and social factors which perpetuate the illness long term

12. MYTH: It is only recently that researchers have finally shown that M.E. has a physical or organic basis

13. MYTH: Only very mild abnormalities have ever been found in M.E. patients

14. MYTH: The only treatments shown to be useful in treating M.E. are CBT (cognitive behavioural therapy) and GET (graded exercise therapy). CBT/GET treatments are useful in 'rehabilitating' M.E. sufferers because M.E. is perpetuated by deconditioning and inactivity. These treatments are also completely safe and there is no risk associated with them for M.E. patients

15. MYTH: All laboratory tests will always come back normal in M.E. patients and so there are no tests that can be done which can confirm a suspected M.E. diagnosis. Diagnosis is extremely difficult

16. MYTH: M.E. is only a diagnosis of exclusion, a wastebasket diagnosis. It is not a distinct disease.

17. MYTH: M.E. can not be diagnosed until after 6 months have passed, M.E. is a gradual onset illness

18. MYTH: There are never any observable physical signs of illness in M.E.

19. MYTH: The symptoms and severity level of the illness remains constant in M.E. If a patient can do something once, they can obviously do it many times; if a patient can do something on one day, of course they will also be able to do it the next day too, or on any other day.

20. MYTH: Research into M.E. is well funded by government

21. MYTH: M.E. primarily or only affects white, affluent and well-educated women

22. MYTH: There are no children who have M.E.

23. MYTH: Most people (or everyone) with M.E. has a ‘type A’ or perfectionist personality and this has caused or perpetuated the illness

24. MYTH: M.E. can result from becoming run down physically or is the end result of high levels of stress, long term stress or childhood trauma or abuse

25. MYTH: M.E. can be caused by the Epstein-Barr virus, glandular fever/mononucleosis, Q fever, HHV6 or Ross River virus

26. MYTH: Evidence exists which suggests or shows that M.E. is caused (partially or completely) by XMRV infection, and this theory fits all the

major facts of M.E. (with no big 'holes')

27. MYTH: The recent XMRV 'CFS' research was conducted on a distinct and 100% M.E. patient group. This research clearly separates M.E. patients from those with 'CFS.'

28. MYTH: The recent XMRV 'CFS' research shows promise in providing a unique test for M.E.

29. MYTH: Evidence exists which suggests or shows that anti-retroviral treatments (perhaps specific to XMRV) are the treatment breakthrough that M.E. patients have been waiting for, for so long. This type of treatment represents real hope (or certainty) of a cure for M.E. patients.

30. MYTH: XMRV is believed to be an important and absolutely vital scientific lead to follow, by all of the M.E. community.

31. MYTH: The term Myalgic Encephalopathy is more medically accurate than the term Myalgic Encephalomyelitis and so using the term Myalgic Encephalopathy is in the best interests of authentic M.E. sufferers

32. MYTH: All those advocacy organisations (and individuals) which publicly state that M.E. (or ME/CFS, CFS/ME or CFIDS etc.) is not ‘all in your head’ are trustworthy and are working for the benefit all M.E. sufferers and are a good source of information about Myalgic Encephalomyelitis.

33. MYTH: All those who state publicly that they believe M.E. to be a purely psychological or behavioural illness are basing their stance on a comprehensive and unbiased examination of the medical evidence and actually believe what they are saying. There is a legitimate scientific debate about whether or not M.E. is ‘real’ or if it is psychological or neurological.

34. MYTH: The name CFS was chosen in 1988 by a group of experienced M.E. clinicians who thought it was the most medically accurate name for the illness at that time

35. MYTH: It is the name CFS itself that is the cause of all the misunderstandings about the illness. If the name Myalgic Encephalomyelitis was renewed (for example) patients would automatically start to get the recognition and respect they deserve, more money for legitimate research and everything else they so desperately need

36. MYTH: Once we have enough hard science behind M.E. – in particular a single diagnostic marker for the illness – things will improve for M.E. sufferers and M.E. will automatically start to get the medical recognition and respect it deserves. (The problem is only that we lack enough science.)

The truth is that every one of those statements is completely untrue despite how often they have been repeated to us and presented as 'facts'. See: The myths about Myalgic Encephalomyelitis for more information. (Reference)

So what do we know about Myalgic Encephalomyelitis so far?
Myalgic encephalomyelitis is a systemic acutely acquired illness initiated by a virus infection which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name Myalgic Encephalomyelitis.) The CNS is diffusely injured at several levels, these include the cortex, the limbic system, the basal ganglia, the hypothalamus and areas of the spinal cord and its appendages. This persisting multilevel central nervous system (CNS) dysfunction is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process.

Myalgic Encephalomyelitis represents an acute change in the balance of neuropeptide messengers, and due to this, a resulting loss of the ability of the CNS (the brain) 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 also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems

including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

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

M.E. is not stable from one hour, day, week or month to the next. It is the combination of the chronicity, the dysfunctions, and the instability, 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 one of the most disabling characteristics of M.E. All of this is not simply theory, but is based upon an enormous body of mutually supportive clinical information spanning over 70 years and printed in reputable medical journals all over the world. (For more information see 'What is M.E.?) (Reference)

There is an abundance of research which shows that M.E. is an organic neurological illness which can have profound effects on many bodily systems. Autopsies have also confirmed such reports of bodily damage and infection. 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 central nervous system immune dysfunction
- there is evidence of central nervous system inflammation and demyelination
- there is evidence of hypomyelination
- there is evidence that Myalgic Encephalomyelitis is a complex, serious multi-system autoimmune disorder (in Belgium, the disorder has now been placed between multiple sclerosis and Lupus)
- there is evidence of significant neutrophil apoptosis

- there is evidence that the immune system is chronically activated (eg. the CD4:CD8 ratio may be grossly elevated)
- there is evidence that natural killer (NK) cell activity is impaired (ie. 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 thermodysregulation; 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
- 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, the eyes, and the brain.)
- 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 Myalgic Encephalomyelitis 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 (Note that this is only a sample of some of the research available, not an exhaustive list.) (Reference)

Often the research that offers a glimmer of genuine hope to Myalgic Encephalomyelitis patients is research into diseases that share significant similarities with M.E. including Alzheimer's, Polio, Parkinson's, AIDS, Lupus, Multiple Sclerosis and so on. (Alzheimer's, Parkinson's and Multiple Sclerosis

are listed along with M.E. under 'Diseases of the nervous system' in the ICD Classifications.) These studies have far more relevance to M.E. patients than almost all of the 'CFS' studies produced which lack scientific merit and use exclusively or almost exclusively non-M.E. patient groups.

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.

For more information:

- For more information on all aspects of M.E. see 'What is M.E.?.
- For more information on the financial and political issues surrounding the creation of 'CFS' and why the disease category of 'CF'S must be abandoned see: Smoke and Mirrors, Who benefits from 'CFS' and 'ME/CFS'? and What is Myalgic Encephalomyelitis? and Why the disease category of 'CFS' must be abandoned.
- M.E. is a distinct, recognisable entity (an acute onset organic neurological illness) that can be diagnosed relatively early in the course of the disease, providing the physician has some experience with the illness. The Nightingale Definition of M.E. (a testable M.E. definition) now also makes diagnosis easier than ever before even for those with no experience with the illness. M.E. is a distinct recognisable well-defined entity, with several unique features, which can very easily be distinguished from various chronic fatigue states, and other unrelated fatiguing illnesses (both psychological and non-psychological) which may qualify for a 'CFS' misdiagnosis. People with M.E. must be diagnosed with M.E. and treated for M.E., according to research which is based on M.E. patients (rather than 'CFS' patients).

  For information on how authentic M.E. is characterised and diagnosed see: Testing for Myalgic Encephalomyelitis, The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List and What is Myalgic Encephalomyelitis? Also highly recommended are the excellent papers by Dr Byron Hyde, a doctor with over 20 years experience with M.E. and regarded by many as today's leading M.E. expert: 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 and The Complexities of Diagnosis and his newest paper: The Nightingale Definition of M.E. Dr Hyde's M.E. textbook is also highly recommended.
- For more information on the vast difference between M.E. and 'CFS' and the important difference between *definitions* and mere terminology, see: The

Terminology Explained and What is Myalgic Encephalomyelitis? 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*.

- Some of the conditions commonly misdiagnosed as 'CFS' are very well defined and well-known illnesses and very treatable – but ONLY once they have been correctly diagnosed. Some conditions are also very serious or can even be fatal if not correctly diagnosed and managed, including Myalgic Encephalomyelitis. (It is not uncommon for people with cancer – which causes significant fatigue – to be misdiagnosed with CFS and to die needlessly due to a lack of appropriate treatment, for example.) Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery. This process must begin with a correct diagnosis if at all possible. **A correct diagnosis is half the battle won.** Every diagnosis of 'CFS' is a misdiagnosis. See: The misdiagnosis of CFS and Where to after a 'CFS' (mis)diagnosis? for more information.
- ***A note on so-called 'subgroups' of 'ME/CFS':*** 'ME/CFS' is just a diversion from the real issues instigated by vested interest groups, the same is true of 'sub-grouping ME/CFS.' It is a nonsense that makes a mockery of legitimate activism. The only relevant subgroups here are M.E., and not M.E. People with Fibromyalgia have FM, and should be diagnosed with FM. To say that FM is a subgroup of 'CFS' or 'ME/CFS' is ridiculous. The same is true of post viral fatigue syndromes caused by Glandular Fever/Mononucleosis, Hepatitis, Ross river virus, Q fever or EBV – and so on. See: The misdiagnosis of CFS and Problems with the use of 'ME/CFS' by M.E. advocates and Why the disease category of 'CFS' must be abandoned for more information.
- For more information on the lack of quality and integrity in almost all M.E. and 'CFS' advocacy groups and how and why most of them have sold patients out to the highest bidder, see: Problems with 'our' M.E. (or 'CFS,' 'CFIDS' or 'ME/CFS') advocacy groups. (This paper is also available in an animated video format.)
- 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.

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This paper will be continue to be updated regularly (at least annually). Please check back at the website periodically to make sure that you have the most up-to-date version of this paper available.

References

All of the information concerning Myalgic Encephalomyelitis on this website is fully referenced and has been compiled using the highest quality resources available, produced by the world's leading M.E. experts. More experienced and more knowledgeable M.E. experts than these – Dr Byron Hyde and Dr. Elizabeth Dowsett in particular – do not exist. Between Dr Byron Hyde and Dr. Elizabeth Dowsett, and their mentors the late Dr John Richardson and Dr Melvin Ramsay (respectively), these four doctors have been involved with M.E. research and M.E. patients for well over 100 years collectively, from the 1950s to the present day. Between them they have examined more than 15 000 individual (sporadic and epidemic) M.E. patients, as well as each authoring numerous studies and articles on M.E., and books (or chapters in books) on M.E. Again, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

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

See the Research & Articles section to start reading through some of the best research and articles on M.E. available.

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

'Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance' Dr Byron Hyde 2006

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

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

The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. Professor Malcolm Hooper 2006

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

M.E. appears to be in this same family of diseases as paralytic polio and MS. M.E. is less fulminant than MS but more generalized. M.E. is less fulminant but more generalized than poliomyelitis. This relationship of M.E.-like illness to

poliomyelitis is not new and is of course the reason that Alexander Gilliam, in his analysis of the Los Angeles County General Hospital M.E. epidemic in 1934, called M.E. atypical poliomyelitis. Dr Byron Hyde 2006

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

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.

Taken from www.hfme.org

- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.

  However, the hearts of M.E. patients only pump barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

  This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.

  If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.

  M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.

- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.

- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

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