

**Smoke and mirrors - An analysis of the scientific legitimacy of the claims that cognitive behavioural therapy (CBT) and graded exercise therapy (GET) are appropriate, safe and effective treatments for people with M.E.**



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It is often claimed that some level of psychiatric causation of Myalgic Encephalomyelitis (M.E.) has been scientifically proven. It is also often claimed that therapies based upon this theory – such as CBT and GET – have also been scientifically proven to be appropriate, safe and effective for these patients.

But does the available research actually support these claims? The answer, many will be surprised to know, is an unequivocal ‘not by a long shot.’ What these studies actually show – if you look at the selection criteria used – is that where patients are selected *solely on the presence of the symptom of chronic fatigue* there is some preliminary evidence that some proportion of these patients may benefit from these interventions (for an as yet uncertain period of time).

But how is this relevant to M.E. patients unless the symptom of chronic fatigue and the neurological illness known since 1956 as Myalgic Encephalomyelitis are exactly the same thing? **What is chronic fatigue, and what is Myalgic Encephalomyelitis?**

Chronic fatigue is a symptom of many different illnesses and has a large number of different and unrelated causes. People with chronic fatigue may be fatigued because of vitamin deficiency, sleep disorder, depression, cancer, burn-out, Multiple Sclerosis, and a large number of other psychiatric and miscellaneous non-psychiatric illnesses. This symptom may persist for weeks, months or years and the severity level can vary from very mild to severe. 20% of the population or more may suffer from some form of chronic fatigue.

Myalgic Encephalomyelitis is not merely a symptom, but instead a distinct *disease*. It has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disease with the code G93.3. Myalgic Encephalomyelitis is a systemic acutely acquired illness initiated by a virus infection which is characterised by 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) which results in dysfunctions and

damage to many of the body's vital 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. is primarily neurological, but symptoms may also be manifested by cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. More than 64 distinct symptoms have been authentically documented in M.E., several of which are unique to the disease. 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.

M.E. can occur in both epidemic and sporadic forms and over 60 outbreaks of the illness have been recorded worldwide since 1934. M.E. can be extremely disabling and in some cases the illness is fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis (Hyde 1992 p. xi) (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999, [Online]) (Dowsett n.d.b, [Online]).

The symptom of chronic fatigue and the distinct neurological illness M.E. each have a very different; cause, symptoms, aetiology, pathology, response to treatment, long and short term prognosis – and World Health Organization classification. Clearly it is a stretch of credibility to say that people with the symptom of chronic fatigue and those with M.E. share any real similarities – let alone that they could somehow represent *the exact same* patient group and be able to be studied interchangeably.

- Note that each of the core features of M.E. (unlike 'fatigue' which is unmeasurable) may be clearly measured and verified using a series of objective tests, see: [Testing for M.E.](#) and [What is M.E.?](#) for more information.

**Thus 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 and very different health problem – the symptom of fatigue.

Does this mean that research conducted using patients with diabetes (for example) can now also be applied to all those who have cancer, Multiple Sclerosis, Lupus or any number of other unrelated problems and diseases, merely because the researchers involved have decided that they would like it to?

In a scientifically enlightened age such as this, how is it possible that the results of studies using one (heterogenous) patient group can be claimed to be entirely relevant in investigating the aetiology and appropriate treatments for a completely separate and unrelated homogenous patient group? How is this scientific or logical? How is this ethical?

### **How have these groups got away with making such false and misleading claims?**

The issue here lies with how M.E. has been defined, or more correctly; how it has been bogusly ‘re-defined.’ The creation of many different definitions of what is now called ‘Chronic Fatigue Syndrome’ is how a particular group of psychiatrists (and others) have superficially ‘bridged the gap’ as it were between these two unrelated patient groups so that they can fraudulently and misleadingly be discussed – to those who are not aware of the subterfuge involved – as if they were one and the same.

### **What is Chronic Fatigue Syndrome? How was it named? How is it defined?**

The new name CFS and the CFS case definition were created by the CDC in the US in 1988 by a board of eighteen members (many of them psychiatrists); few of which had studied either an epidemic of M.E., or any patients with the illness. This new criteria failed to select patients using any past or current research or lab work relevant to M.E., excluded the cardinal symptoms and signs of M.E. and instead focused almost entirely on ‘fatigued persons.’ Although the new name and accompanying definition were created in response to an outbreak of what was unmistakably M.E., both bore so little relationship to the existing history and literature on M.E. that the three more experienced members of the board refused to sign the final document. They withdrew themselves from the (CDC) definitional committee because the proposed new name for the illness and the definition that went with it were just too different from the Myalgic Encephalomyelitis with which they were so familiar (Hooper et al. 2001 [Online]).

Nearly 20 years later there are now more than 9 different CFS definitions. In the two most commonly used definitions – the US 1994 Fukada (or CDC) definition and the 1991 UK Oxford definition – the only essential symptom required for the diagnosis of ‘CFS’ to be made is ‘chronic fatigue.’ Both of these definitions are designed to expressly *include* those with somatisation disorders (or other non-major psychological or psychiatric disease) as patients who have physical signs of illness (as is the case with every M.E. patient) are specifically excluded from the diagnosis. By definition patients with neurological disease, including M.E., have been excluded from study using these criteria. Neither of these definitions (nor any of the ‘CFS’ definitions) defines a neurological condition and indeed they are each far too vague to define *any* single and distinct disease. All either of these definitions ‘define’ is a heterogeneous population of sufferers from misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue (Hooper a. [Online]).

Today when the term CFS is used what is being referred to may be patients with/facts relating to any combination of: 1. Miscellaneous psychological and non-psychological fatigue states (including somatisation disorder) 2. A self limiting post-viral fatigue state or syndrome (eg. following glandular fever.) 3. A mixed bag of unrelated, misdiagnosed illnesses (each of which feature 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 (despite the fact none of the CFS definitions describes M.E., many M.E. sufferers are unfortunately given a ‘CFS’ misdiagnosis).

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 (2006, [Online]).

‘CFS’ and M.E. are anything but synonymous terms. The vast majority (an estimated 95%+) of the research and articles available today which use the term and definitions of ‘CFS’ are not in any way concerned with, or relevant to, Myalgic Encephalomyelitis patients.

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

In the 1980s in the US (where there is no NHS and most of the costs of health care are borne by insurance companies), the incidence of ME escalated rapidly, so a political decision was taken to rename M.E. as “chronic fatigue syndrome”, the cardinal feature of which was to be chronic or on going “fatigue”, a symptom so universal that any insurance claim based on “tiredness” could be expediently denied. The new case definition bore little relation to M.E.: objections were raised by experienced international clinicians and medical scientists, but all objections were ignored... To the serious disadvantage of patients, these psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to government 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’ and by ‘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 has 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. Wessely’s claims (and those of his colleagues around the world) have flooded the UK (and worldwide) literature to the extent that medical journals rarely contain any factual and unbiased information on M.E. Thus 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 having a vested interest in how M.E. is managed have been exposed.

The government funded research produced by this group continues to be rigorously criticised on the grounds that it is methodologically flawed and biased and that it relies on a highly selective and misrepresentative choice of references, and too often cites their own studies as the sole or primary references. Despite this, and the fact that this coterie of psychiatrists has a number of outrageous conflicts of interest and proven affiliations with corporate industry they have managed to assiduously infiltrate all the major institutions – including government – directing funding for M.E. research into an exclusively psychiatric model of the illness; and which involves studying ‘fatigue’ sufferers instead of those with M.E. All under the ‘anything-goes’ banner of ‘CFS’ (Mar 2004, [Online]) (Hooper 2003, [Online]) (Hooper et al. 2001, [Online]).

This is the sole reason why the charade that M.E. could be a psychiatric or behavioural ‘fatiguing’ disorder or even a ‘aberrant belief system’ continues: not because there is good scientific evidence – or *any* evidence – for the theory, or because the evidence proving organic causes and effects is lacking – but 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 comments, these ridiculous financially motivated theories bear as much relation to legitimate science ‘as Astrology does to Astronomy’ (1999b [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.

‘CFS’ makes getting disability payouts almost impossible, as there are no tests whatsoever that can be used to prove the existence of ‘CFS’ and because there is also so much bogus ‘information’ available about how easily and successfully ‘CFS’ can be managed or even cured. The CDC (and all other) ‘CFS’ definitions define ‘CFS’ as a psychological illness – which many health insurance policies explicitly exclude and many limit to two years’ cover. ‘CFS’ allows insurance companies and governments to evade or at least greatly limit claims all over the world. **If the US has only had a universal healthcare system in place in the 1980s, and there hadn’t been obscene profit to be made by denying the existence of serious organic illnesses, this ‘CFS’ mess would never have happened.**

Among his 53, largely undeclared, conflicting interests Wessely is a member of the supervisory board of a company named PRISMA. This same company is being paid many millions of pounds to supply ‘rehabilitation’ programs (such as CBT and GET) to the NHS for use on ‘CFS’ patients (Mar 2004, [Online]). Wessely is also an officer of the insurance giant UNUM.

The facts on Wessely’s colleagues are equally disturbing. Other members of the Wessely school with similar indisputable long-term commitments to the

medical insurance industry are Michael Sharpe, Professor Mansel Aylward, Anthony Cleare, John Locasio and Peter White – Wessely’s closest colleagues. Peter White is one of the chief medical officers for insurance company Swiss Re and their other “CFS experts” are Michael Sharpe and Simon Wessely, and they also use psychiatrist Anthony Cleare (a frequent co-author with Wessely). LoCascio of UNUM advised the UK DWP (Welfare Office) on welfare reform while Professor Aylward was in charge of UK DWP and then director of UNUM’s research establishment at Cardiff University (Hooper 2003, [Online]) (Hooper et al. 2001, [Online]) (Williams 2007, [Online]). The list goes on. In the US in 2004 Commissioner John Garamendi described UnumProvident as ‘an outlaw company’ and also stated that, ‘It is a company that for years has operated in an illegal fashion’ (Rutherford 2007, [Online]).

Other insurers involved include: Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life and Permanent Insurance, and as Re-insurers, the massive Swiss Re. The goal of these groups has clearly been to prevent insurance cover for M.E. patients (those with a psychiatric label are denied medical insurance cover), to prevent disability payments to them and to prevent successful liability lawsuits and maintain the supremacy of their industries (Hooper 2003, [Online]) (Hooper et al. 2001, [Online]) (Williams 2007, [Online]) (Rutherford 2007, [Online]).

This group has also driven government policy on M.E. in the UK to an overwhelming extent. Wessely is adviser to the UK government and his wife (a GP and psychiatrist) is Senior Policy Adviser to the Department of Health. Wessely was also recently reprimanded by the World Health Organisation (WHO) for attempting to subvert the ICD definition of Myalgic Encephalomyelitis due to the fact that he did not, as he claimed, have the authority to issue a WHO definition (Hooper 2003a, [Online]) (Hooper et al. 2001, [Online]) (Marshall & Williams 2005a, [Online]).

This large scale deception by insurance companies has been made possible largely because of the fact that holding some of the most powerful advisory positions in government (as some of these vested interest psychiatrists do) does not seem to be mutually exclusive with also having direct ties and allegiances to industry, even if those industries are directly affected by the decisions made by the government department/adviser in question (as the giant chemical, pharmaceutical and insurance industries are in M.E.) (Hooper 2003a, [Online]). As 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.

Given that what Wessely promotes is contrary to the established scientific evidence, how does he manage to maintain such power and control? Many knowledgeable people believe he maintains it by singing the desired political tune; by scientific misconduct; by manipulation of other people's published work; by flawed methodology; by deception and by the circularity of self-references. Substantial evidence clearly reveals that in pursuit of his personal ideology or, alternatively, that of his corporate masters, Wessely abuses the scientific process. The implementation of his personal philosophy is not based on medical science and has had devastating consequences, not just for sufferers of M.E. but for their families as well.

There is a gross mismatch between the severity and complexity of M.E. and the medical and public perception of the disorder, but until Simon Wessely is held to public account, and medical professionals and public alike are informed and educated about the reality of M.E., this will continue (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 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 undoubtedly 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, and other unrelated illnesses, for the benefit of various (proven) financial and political interests. The resulting 'confusion' between the distinct neurological disease M.E. and the man-made bogus disease category of 'CFS' has caused an overwhelming additional burden of suffering for those who suffer from neurological M.E. and their families. **It's a big 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 1999b, [Online]).

- To read more 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 also A Brief History of Myalgic Encephalomyelitis & An Irreverent History of CFS by Dr Byron Hyde
- Note that while the unmodified Fukuda or CDC criteria is commonly used for research worldwide the only definitions used in studies which have shown beneficial effects from CBT and GET are those which select patients solely on the presence of the symptom of fatigue ie. Oxford criteria or modified Fukuda criteria. These definitions select those patients most likely to be mildly ill, and those most likely to have psychological or behavioural issues causing their fatigue.
- For more information on Wessely (etc) and more detail on the corporations involved see: What is ME? What is CFS? Information for Clinicians & Lawyers, The Mental Health Movement: Persecution of Patients, Inadequacy of the York (2005) Systematic Review of the CFS/ME Medical Evidence Base, Politically-modified Research, Wessely, Woodstock and Warfare and Unanswered Questions: do inconsistencies matter in medicine? Plus also: To set the record straight about Ean Proctor from the Isle of Man, Another Meadow? and Considerations of some issues relating to the published views of Psychiatrists of the Wessely School in relation to their beliefs about the nature, cause and treatment of myalgic encephalomyelitis (ME). See also many more articles on this topic – and on the politics of ‘CFS’ in the US at the CDC and in Australia – in Section 3 of this guide.

**In addition to insurance companies, who else benefits from the ‘CFS,’ ‘ME/CFS,’ ‘CFS/ME’ and Myalgic ‘Encephalopathy’ and so on, fictions continuing? From M.E. and ‘CFS’ not being clearly separated and all patient groups involved being correctly diagnosed and treated based on science?**

Other groups which benefit financially, politically or in other ways include the following:

- A. Governments
- B. The vaccine industry
- C. The chemical industry
- D. Psychiatrists

- E. 'CFS' doctors
- F. Medical doctors
- G. The media (including medical journals)
- H. CFS' or 'ME/CFS' (and other) groups that sell vitamins and other supplements to 'CFS' patients
- I. CFS' or 'ME/CFS' (etc.) so-called patient support and advocacy groups.

### **How have these groups each managed to avoid society's various checks and balances?**

Medical insurance companies could not have achieved the current state of affairs alone, with the concept of 'CFS' as their only weapon. All of the groups listed above *collaborate*.

There are different corporate and government interests involved, and they share a financial interest in suppressing M.E. and promoting 'CFS,' so they work together. For example, pharmaceutical companies fund the research, psychiatrists define the illness, assess the patient, advise the government departments in creating definitions and policy, insurance companies rely on official definitions and policy and employ psychiatrists to assess the patients, government welfare departments use the definitions and policy in assessing claimants, sell-out so-called advocacy groups support the latest government 'awareness' campaign in return for getting government funding. Most journalists act as mere stenographers when they write about 'CFS' rather than investigative journalists; they copy the government press releases almost word for word rather than doing any genuine research into the facts. This is just a brief summary of a small number of the deals we know about. There are clearly many more.

That is how these groups have been successful and how they have for the most part avoided society's checks and balances, by collaborating with each other to protect their shared financial or political gains. A group acting alone can be stopped, by making other groups aware of what is happening. But what happens when almost all of the different groups which are there to protect the interests of the victims are actually in on the scam themselves? What do the victims do then? How does one convince others of the truth when so many seemingly benign companies or supposedly patient-based organisations are producing so much completely mutually supportive and superficially convincing propaganda? This is the problem facing M.E. patients.

What makes the problem even worse is that unlike AIDS patients who in the early stages of their illness are able to march and rally and organise protests, most M.E. patients are far too ill to participate in such activism efforts. They

may often not even be well enough to read the basic facts about what is happening. Thus nothing has changed for the better in the 20 years since the 'CFS' scam began. Thanks to the increasing psychological emphasis of succeeding CDC definitions of 'CFS,' 'ME/CFS' replacing M.E. in official policy in UK, Australia and Europe, and the covert infiltration of patient advocacy groups by vested interest groups, and so on, the level of abuse affecting M.E. patients is only *worsening* as time goes on.

- For more information on this topic, including how each of these groups benefits from 'CFS' and 'ME/CFS' see: [Who benefits from 'CFS' and 'ME/CFS'?](#)

Thus despite the misleading claims to the contrary made by these vested interest groups, no evidence exists which shows that cognitive behavioural therapy (CBT) or graded exercise therapy (GET) are appropriate, useful or safe treatments for Myalgic Encephalomyelitis patients. Studies by these groups (and others) involving miscellaneous psychiatric and non-psychiatric 'fatigue' sufferers, and their response to these treatments, have no more relevance to M.E. sufferers than they do to diabetes patients, patients with multiple sclerosis or any other illness. Thus, patients with M.E. are being prescribed these treatments on what amounts to a 'random' basis medically and so the questions need to be asked:

### **What is the effect of graded exercise therapy (GET) on Myalgic Encephalomyelitis (M.E.) patients?**

As (bad) luck would have it, graded exercise programs are probably the single most inappropriate treatment that a M.E. sufferer could be recommended to undertake. This is because one of the unique features of authentic M.E. is exercise intolerance – that patients worsen with even trivial levels of activity or exercise. Exercise or exertion intolerance is one of the many things which separates Myalgic Encephalomyelitis so distinctly from various post-viral fatigue states or other illnesses involving 'chronic fatigue.' People with M.E. do not improve with exercise. They cannot; exercise intolerance is a large and essential part of *what M.E. is*. Veteran M.E. expert Dr Ramsay explained that this unique characteristic: 'is virtually a sheet-anchor in the diagnosis of Myalgic Encephalomyelitis and without it a diagnosis should not be made' (1986, [Online]).

This essential feature of M.E. is characterised by a unique form of paralytic muscle weakness whereby muscles perform normally to begin with but after even a minor degree of physical effort; three, four or five days, or longer, elapse before full muscle power is restored. This affects all muscles including the heart

and is very different from mere ‘fatigue.’ (Ramsay 1986, [Online]) (Hyde 2003, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999, [Online]) (Dowsett n.d.b, [Online]).

Doctors who have experience with M.E. (and can tell the difference between authentic M.E. and various unrelated fatigue states) and the leading M.E. experts all concur; exercise can have many harmful effects on patients both in the short- and long-term. The following comments which illustrate this point are provided by some of the world’s leading M.E. experts, all of whom have been specialising in M.E. for many decades and each of whom has seen literally *thousands* of M.E. patients;

**1. Dr Melvin Ramsay**, a UK doctor who specialised in M.E. for more than thirty years, from the Royal Free Hospital M.E. outbreak of 1955 until his death in 1990, and who is credited with having written some of the most accurate description of the illness to date, 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.** Those who are given complete rest from the onset do well. Those whose circumstances make adequate rest periods impossible are at a distinct disadvantage, but no effort should be spared to give them the all-essential basis for successful treatment. 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’ (Ramsay 1986, [Online]).

**2. 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. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion. The prescription of increasing exercise is such a situation (or in the early stage of the illness when the patient desperately needs rest) can only be counter-productive’ and ‘This illness is distinguished from a variety of other post-viral states by a unique clinical and epidemiological pattern characteristic of enteroviral infection. Prompt recognition and advice to avoid over-exertion is mandatory’ and ‘The prescription of increasing exercise can only be counter-productive.’

Dr Dowsett states about M.E. patients that, '**20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.**' According to Dr. Elizabeth Dowsett, any M.E. patient can also be stopped from deteriorating further and at least stabilised (if not in time experiencing some level of improvement) through receiving appropriate care and being allowed to get the needed level of rest (providing that the patient has not already been exposed to unrecoverable levels of overexertion) (Dowsett & Ramsay et al. 1990) (Dowsett 2000, [Online]) (Dowsett 2001a, [Online]) (Dowsett n.d.b., [Online]).

**3. Dr Byron Hyde** explains in his M.E. textbook that it has been found that those patients with M.E. who returned to work soon after becoming ill or while they were still seriously or severely ill – instead of having an extended period of rest and recovery – are at risk of causing an abnormal increase in damage 'to a heart muscle already vulnerable and under attack from an acute viral infection' and that those who do not, or cannot, rest in the early stages of M.E. potentially create 'a physical injury to the myocardium, cardiac pacemaker cells or their autonomic control.' Dr Hyde explains that:

This is not just clinical supposition, there is a strong basic for this belief of work or exercise potentiated heart damage in the literature. It is well known that enteroviruses may cause chronic cardiac disease as well as major neurological injury. Kandolf states that "enteroviruses are capable of causing dilated cardiomyopathy of sudden onset or lead to a variety of common arrhythmias." Utilizing mouse models, Wilson and again Reyes demonstrated that Cocksackie infected [enterovirus infected] mice, forced to swim to the point of exhaustion during the acute phase of infection, developed chronic heart disease whereas Cocksackie infected mice who were allowed to rest during the acute phase, did not develop chronic heart disease.

M.E. represents a possibility of serious cardiac injury primarily in patients who exercise or maintain exhaustive work efforts during the onset of their illness. It is possible that some of these patients who die and other that develop major cardiac changes are never recognised as M.E.

With both CNS and CVS disease, chronicity may be provoked by maintaining strenuous exercise and work levels.. Early patient activation may represent serious cardiovascular danger to patients [with M.E.]. The strange concept of waiting 6 months to diagnose a classical case of M.E. [brought about by the confusion between M.E. and 'CFS'] is unnecessary and fraught with potential danger to the patient. Such a diagnostic delay may create legal consequences for the physician. Physicians who take an early

aggressive approach in physically activating these acute stage patients may do so at both their and their patient's peril (Hyde & Jain 1992a, pp. 375-383).

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (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. (This also includes doctors such as A. Gilliam, W.H. Lyle, Elizabeth Bell of Ruckhill Hospital, James Mowbray of St Mary's, and Peter Behan). The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling (Hyde 2007, [Online]) (Hyde 2006, [Online]).

Dr Hyde explains that enteroviral infections are able to cause:

- a. a chronic host infection
- b. major or no cardiac disease depending on the virulence of the subtype
- c. cardiac injury dependent upon the sex of the patient and of the level of physical activity of the patient during the acute or infectious stage
- d. cardiac disease depending upon the immunological variability of the host (Hyde & Jain 1992a, p. 40).

An enterovirus also 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) (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]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92) (Richardson 1999, [Online]).

Dr Byron Hyde explains that the vascular and cardiac dysfunctions seen in M.E. are often the most obvious set of dysfunctions when looked for, and are the cause of a significant number of M.E. symptoms. Dr Byron Hyde also writes, 'I have some M.E. patients with a circulating red blood cell volume less than 50% of expected and a very large number with the range of 60% to 70%. What this test means is that blood is pooling somewhere in the body and that this blood is probably not available for the brain. When blood flow to the heart decreases sufficiently, the organism has an increased risk of death. Accordingly, the human body operates in part with pressoreceptors that protect and maintain heart blood supply. When blood flow decreases, pressoreceptors decrease blood flow to noncardiac organs and shunt blood to the heart to maintain life. This, of course, robs those areas of the body that are not essential for maintaining life

and means the brain, muscles, and peripheral circulation are placed in physiological difficulty.’ This physiological difficulty is exacerbated by physical and mental activity and orthostatic stress.

Dr Byron Hyde goes on to say that, ‘**In MRI spectography of arm muscle of M.E. patients, it has been shown that because of an abnormal buildup of normal metabolites, the muscle cell actually shuts down to prevent cell death.**’ Dr Hyde explains that this is what is happening to the M.E. patient’s cell physiology in the brain, and in muscle as a result of certain levels of physical and mental activity; there is ‘cell field shutdown’ to prevent the death of the cell (Hyde 2003, [Online]). Dr Byron Hyde explains in The Nightingale Definition of M.E. that,

Possibly due to the fact that some Fibromyalgia patients can be improved by a gradual increase in exercise, or possibly due to the so called protestant ethic that all you have to do to get better is to take up your bed and walk, some physicians have extended the concept of passive or forceful increased exercise to Myalgic Encephalomyelitis patients. This is a common and potentially dangerous, even disastrous misconception. If the M.E. patient conforms to the guidelines set out in this definition, the insurance company can only make the patient worse by instituting progressive aggressive forced physical and intellectual activity. M.E. is a variable but always, serious diffuse brain injury and permanent damage can be done to the M.E. patient by non-judicious pseudo-treatment (2007, [Online]).

As these brief comments show, the adverse response to physical activity in M.E. patients is well-documented and not ‘medically unexplained.’ It is also worth noting that *none* of these abnormalities can be explained by ‘deconditioning’ – the supposed reason for the recommendation of therapies such as GET (MESA 2007, [Online]).

- These brief comments on the effects of GET are taken from the far more detailed and comprehensive paper: The effects of CBT and GET on patients with Myalgic Encephalomyelitis, please see this paper for more information.

Surveys of M.E. patients on the effects of GET illustrate the accuracy of these findings only too well:

- In 1998 a survey of over 3000 UK M.E. patients found that the single most harmful strategy was graded exercise therapy. 50% of respondents who had tried GET indicated that graded exercise had made their condition worse.. The most helpful strategies were: a) Pacing activity with rest: 90% b) Bed rest: 89% (Jones 1998, [Online]).

- In 2004 a survey of severely affected M.E. sufferers again found that graded exercise was by far the single most harmful treatment. 95% said that graded exercise was ‘unhelpful’ while a shocking 82% reported that it had made their condition worse. A significant number of those surveyed indicated that they were not severely affected *before* GET (25% M.E. Group 2004, [Online]). Thus GET should not be considered safe for M.E. sufferers of any severity.

The way the bodies of people with M.E. react to exercise is abnormal in a number of different ways. These abnormalities are so pronounced that exercise tests are one of the series of tests which can be used to confirm a suspected M.E. diagnosis.

- See [Testing for M.E.](#) for more information about the series of tests which can be used to confirm a suspected M.E. diagnosis (including exercise tests, tests of orthostatic intolerance, and of the heart-rate using tilt-table testing and Holter monitors.) To read more articles, research and books by these authors (and others) which explain these abnormalities in more detail see: [Articles sorted by author](#) and [Myalgic Encephalomyelitis research and articles](#).

Strong evidence exists to show that exercise can have extremely harmful effects on M.E. patients; permanent damage may be caused, as well as disease progression: recent research has shown that postural stress (as well as exercise) exacerbates cardiac insufficiency in this disease. Patient accounts of leaving exercise programs much more severely ill than when they began them; wheelchair-bound or bed-bound or needing intensive care or cardiac care units, are common. The damage caused is often very severe and may be either long-term or permanent. . Thus some patients are still dealing with the severe physical effects of inappropriate advice to exercise (or formal GET programs) 5, 10, 15 or more YEARS afterward and for some patients this damage appears to be permanent.

In addition to the risk of relapse, sudden deaths have also been reported in a small percentage of M.E. patients following exercise. As [Dr. Elizabeth Dowsett](#), explains; ‘20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.’ Dr Dowsett has estimated the death rate of M.E. to be 3% . (This figure however also includes other causes of death including organ failure, another common cause of death in M.E. patients) (2000, [Online]) (2001, [Online]).

It is vital that M.E. patients avoid physical over-exertion and are never encouraged to be active beyond their individual limits particularly in the early

and acute stages of the illness, but also at *any* stage of the illness as this can greatly damage a patient's chances for future improvement or recovery. Graded exercise *cannot* improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E. (Ramsay 1986, [Online]) (Hyde 2003, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 – 43) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999, [Online]) (Dowsett n.d.b, [Online]).

- In M.E., the body no longer responds appropriately to physical activity, cognitive exertion, sensory input or orthostatic stress. Thus relapse is not caused solely by physical activity. For more information see: [The ultra-comprehensive Myalgic Encephalomyelitis symptom list](#)

### **What is the effect of cognitive behavioural therapy (CBT) on Myalgic Encephalomyelitis (M.E.) patients?**

Compared to the physical devastation caused by GET, CBT would seem at first glance to be the softer option of the two interventions; but this is not always the case. There are two different types of CBT that M.E. sufferers may be given and the effect on patients varies greatly depending on which type is used:

1. The first type of CBT respects that there is an organic illness present which is largely irreversible (and which cannot be improved by CBT), but aims to help a patient cope better with the limitations caused by their illness (Carruthers et al. 2003, [Online]).
2. The second type of CBT is based on the premise that the patient's impairments are entirely due to 'wrong thinking' and that the pathophysiology of the illness is entirely reversible and perpetuated solely by a patient's 'false illness beliefs.' According to this theory the therapy is potentially curative (Carruthers et al. 2003, [Online]).

Surveys of M.E. patients on the effects of cognitive behavioural therapy found:

- The (aforementioned) 1998 survey of over 3000 UK M.E. patients found that CBT was the least effective treatment covered in the questionnaire. Of those who had tried CBT, 55% indicated that the treatment had made no difference while 22% indicated that they had been made worse by CBT (Jones 1998, [Online]).
- The (aforementioned) 2004 survey of severely affected M.E. sufferers also found that cognitive behavioural therapy was one of the most unhelpful treatments for M.E. Fully 93% of those who had tried CBT said that it was unhelpful (the only treatment with a worse rating was GET) (25% M.E. Group 2004, [Online]).

**The hypothesis behind the first type of CBT** is reasonable. This type of CBT will likely do the vast majority of mild - moderately affected sufferers little harm (if also very little good), while a small percentage may find it useful in improving the way they cope with the illness emotionally. A significant percentage of patients will also be made worse by CBT. Even this type of CBT however (or any other), is not appropriate for any severely affected sufferer who is not physically able to cope with the physical and cognitive rigours of such a treatment (Carruthers et al. 2003, [Online]).

One of the main M.E. misconceptions is that while walking a few steps must of course require additional bodily resources and additional cardiac output, time spent thinking, looking, listening or experiencing other sensory stimuli does not. But this is not the case. Not only physical effort, but also cognitive effort, requires additional resources which an M.E. patient may not have. The brain contains some 100 billion neurons connected to some 10,000 relay stations and this enormous electrical activity creates a massive need for energy and other bodily resources. The brain uses up to 25% of the entire body's demand for glucose, 25% of the blood pumped from the heart goes to the brain and the brain also needs 25% of the body's oxygen supply. (Blood supplies nutrients like glucose, protein, trace elements, and oxygen to the brain.) So of course, every extra second of 'electrical activity' – every thought, every feeling, every noise heard or sight seen – requires additional cardiac output, makes additional oxygen and glucose demands, and so on, in just the same way as does a physical activity such as walking; if not more so. So in addition to physical activity, the list of things that can cause similar severe relapse in M.E. patients also includes cognitive exertion, sensory input and orthostatic stress. Anything that makes the body work harder or have to adjust in some way, in effect (Dowsett n.d. d, [Online]).

Thus any type of CBT will cause severe relapse in those who are severely affected in this way thus CBT can NOT be considered safe for all M.E. sufferers (Carruthers et al. 2003, [Online]).

**The hypothesis behind the second type of CBT** however, is far from reasonable. This unscientific form of CBT (which ignores the demonstrated biological pathology of the illness) seeks to disregard the patient's autonomy and experience of their illness. It tells them to ignore their symptoms. When, inevitably, this causes significant physical relapse, patients are told that this is entirely their own fault; that they must not be trying hard enough to get well and must still not be thinking 'correctly' about their illness. Patients are accused of 'choosing' to remain unwell because they are supposedly 'enjoying the sick role' (Carruthers et al. 2003, [Online])

CBT to convince a physically ill person that he/she does not have a physical disorder is disrespectful, inappropriate and cruel. It places an additional (and bogus) psychological burden on a person already suffering with severe physical illness, and can cause significant psychological harm. M.E. expert Dr. Elizabeth Dowsett explains about CBT: ‘Whereas any regime which can encourage patients with depression to discard or distract their damaging unrealistic morbid thoughts is helpful, patients with ME are usually capable of greater insight and understanding about their illness. Unfortunately, ME sufferers are too often denied care in our society, so it is essential that they should remain as well informed as possible about treatment options and not ‘brainwashed’ into disbelieving their own symptoms’ (n.d.b [Online]).

It is undoubtedly children with M.E. and their families who pay the highest price where CBT is involved however. Children with M.E. are not exempt from such interventions and this is often far more detrimental to children as compared to adults. As authors Verillo and Gellman explain: ‘To throw disbelief in the face of a child who not only has all the symptoms of [M.E.] but is terribly frightened and in profound need of reassurance is not only cruel, it is detrimental to the child's future emotional growth’ (Verillo & Gellman 1997 p. 327).

Equally concerning is the fact that because it is harder to pin the blame for the illness on depression or anxiety with children, the parents are often blamed instead. The ‘family dynamic’ may be blamed for causing the child’s illness and parents of these ill children have actually been charged with neglect or accused of actually making their children ill themselves (false accusations of Munchausens by proxy). Some parents have lost custody and their children have been placed in foster care. Children have also been forcibly removed from the home and forced to undergo CBT and GET (and worse). All of this while the child continues to be seriously physically ill and not receive any sort of appropriate medical care.

This abusive form of CBT can undoubtedly cause significant psychological harm, but it is these additional associated burdens; physical relapse, the withholding of basic medical care, the removal of children from their parents and parents being falsely charged with making their children ill themselves (etc.) which combine to make this form of CBT so harmful. Thus the negative effects of CBT can sometimes be equally as devastating as those of GET, or in some cases, worse (for sufferers and their families).

- These brief comments on the effects of CBT and GET are taken from the more detailed and comprehensive paper: The effects of CBT and GET on

patients with Myalgic Encephalomyelitis, please see this paper for more information.

- For more information about forced exercise and other ‘treatments’ used on M.E. children see: What is Myalgic Encephalomyelitis? Extra extended version

### **Clearly, CBT and GET are at best useless and at worst extremely harmful for M.E. patients**

Despite this, people with M.E. are routinely being recommended these treatments while also being assured that they are completely safe.

These treatments are also not just being offered to M.E. patients solely on a voluntary basis; many have been treated as psychiatric patients against their will. (Or against the will of the parents of children with M.E., as described previously). In some cases it is a condition of receiving medical insurance entitlements that M.E. patients first undergo ‘rehabilitation’ such as CBT and GET programs. This is also true of government welfare entitlements as Professor Malcolm Hooper explains:

[In the UK] many patients are simply too sick to be forced to attend psychiatric units and to participate in compulsory “management strategies” which involve exercising, but if they fail to attend, they are deemed not to want to get better and their State benefits are withdrawn because of Wessely’s dogmatic advice to Government that ME is nothing more than an “aberrant illness belief”. There are many such known cases, including those in which ME patients have been threatened with being sectioned (ie. compulsorily detained under the Mental Health Act) unless they comply with psychotherapy. (2003, [Online])

It is also of great concern that 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) around half have no contact with the health service at all as they are seldom able to obtain housecalls, for example. (Dunn 2005, [Online]). 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 or support. (Hooper 2003, [Online])

- For more information on this see: Comments from Greg Crowhurst of the 25% M.E. Group to the Gibson Enquiry. Many more articles on this topic are also available in Section 3, Section 5 and Section 6 of this guide.
- A recent example of a 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 not long after this ‘treatment.’ For information on this tragic case see: [What is Myalgic Encephalomyelitis? Extra extended version.](#)

## **Conclusion**

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

Substantial evidence 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.

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 premises of M.E. as a debilitating organic neurological illness. Thus 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 (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999, [Online]) (Dowsett n.d.b, [Online]). M.E. is not ‘medically unexplained’ (or ‘unexplainable’) and 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.

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.)

The bogus disease category ‘CFS’ has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various psychiatric fatigue states and various unrelated fatigue syndromes (etc). People with M.E. however are not the only patient group to be negatively affected by this politically-modified science. It is common for patients with a variety of different illnesses with fatigue as a symptom to be misdiagnosed as having ‘CFS.’ These may be patients with a large number of varying conditions as described previously. Patients ‘diagnosed’ with Fukuda CFS (or any other CFS definition) may have any one of a number of different illnesses. It is vitally important that each of these patients discovers their true diagnosis so that they may finally receive appropriate treatment and support. 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. Lumping these disparate patient groups together under a vague and meaningless category of ‘fatiguing illnesses’ only hinders each of the patient groups involved in their battle to regain their health.

There are also a variety of negative impacts on doctors and the public (and others) caused by the ‘CFS’ insurance scam. As one M.E. advocate explained recently: ‘So many abnormalities have now been shown to occur regularly in cases of authentic ME that it is not only bad science to attempt to dismiss, ignore or deny a reality that can be scientifically measured, but to continue to do so must, as others have noted, border on the criminal (Marshall & Williams 2006, [Online]). This is particularly relevant to those doctors which recommend CBT or GET to their patients. Whether they are aware of it or not, these doctors are leaving themselves open to being sued when (inevitably) a proportion of these patients (those with M.E.) are made sicker by these therapies, or being sued by the families of M.E. sufferers who die as a result of these inappropriate interventions.

‘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 the additional avoidable deaths they are causing. These groups are acting criminally. This scam is tissue thin and very easily

discovered if one merely takes a small amount of time to look at all of 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 and 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 beyond sick.

*The only groups which gain from this 'CFS' confusion are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.*

### **So where do we go from here?**

Sub-grouping different types of 'CFS' or renaming would achieve nothing and only create yet more confusion – which the corporations involved would no doubt continue to take advantage of, to the continued detriment of patients. The only way forward is that:

**1. The artificial disease category 'CFS' must be abandoned.** There is no such disease/s 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' and 'Myalgic Encephalopathy' and others).

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

opportunity. Each of the patient groups involved must be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group.

Dr Byron Hyde explains that doctors must return to the age-old medical principals of correct diagnosis (a) careful history, (b) detailed physical examination and (c) appropriate investigation (2006, [Online]).

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

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

The only thing that makes any sense is for patients with Myalgic Encephalomyelitis, 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 and the 70 year history of neurological M.E. – is Myalgic Encephalomyelitis.

People with M.E. must immediately stop being treated as if they are mentally ill, or suffer with a behavioural illness, or as if their physical symptoms do not exist or can be improved with ‘positive thinking’ and exercise, or mixed in with various ‘fatigue’ sufferers in any way.

All forms of GET, and the abusive and unscientific form of CBT, must be banned for all M.E. patients. It is illogical and unethical (and a gross violation of basic human rights) that patients be routinely subjected to treatments which have virtually zero chance of providing any benefit and such a high risk of serious and long-term harm (or death). People with M.E. must also be given access to basic medical care, financial support and other appropriate services (including funding for legitimate M.E. research) on an equal level to what is available for those with comparable illnesses (eg. multiple sclerosis or Lupus).

Currently many physicians and most consultants (for example, cardiologists, neurologists, chest physicians, rheumatologists, immunologists) have virtually no accurate knowledge about M.E. and therefore underestimate both its seriousness and the multi-system dysfunction it causes, so patients are simply dismissed and abandoned without support. This must change (Hooper & Marshall 2005a, [Online]). The facts about M.E. must again be taught to medical students, and included in mainstream medical journals and already practicing physicians must be brought up to speed about M.E. It must be as unacceptable for physicians to be ignorant about M.E. as it would be if doctors were ignorant of the basic facts of Multiple Sclerosis, diabetes or any other common and serious disease. M.E. expert Dr Elizabeth Dowsett explains that:

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

There is no denying that the facts about Myalgic Encephalomyelitis may well be quite inconvenient to any number of powerful and unethical corporations as well as some doctors, politicians, media, and members of the public who have been operating under false pretences for so long with regards to this disease. **But inconvenient facts or not, it is facts that they remain.**

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This text forms the introduction to a 100 page + CBT and GET database.

The database 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' paradigm of M.E. and the use of CBT and GET on M.E. patients – as well as a large number of patient accounts of CBT and GET. To access the database go to:

[www.hfme.org/cbtandget.htm](http://www.hfme.org/cbtandget.htm)

To print or save a copy of this text (or the entire database) in Word or PDF format, see the Downloads section.

**For further information:**

- See What is M.E.? for more information on all aspects of M.E.

- For whose benefit was ‘Chronic Fatigue Syndrome’ created, and for whose benefit is it so heavily promoted despite its utter lack of scientific credibility? Who benefits from the artificial ‘CFS’ construct? Who benefits from Myalgic Encephalomyelitis and ‘CFS’ being mixed together through unscientific concepts such as ‘CFS/ME’ and ‘ME/CFS’ and Myalgic ‘Encephalopathy’? Who benefits from the facts of M.E. remaining ignored, obscured and hidden in plain sight? See: [Who benefits from 'CFS' and 'ME/CFS'?](#)
- To read a text which deals solely with the medical issues surrounding CBT and GET on M.E. patients see: [The effects of CBT and GET on patients with Myalgic Encephalomyelitis.](#)
- See also [Hospital or carer notes for M.E.](#) and [Why patients with severe M.E. are housebound and bedbound.](#)
- For some excellent overviews on this topic see: [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, The Complexities of Diagnosis and Nightingale Definition of M.E. plus Myalgic Encephalomyelitis \(ME\): a review with emphasis on key findings in biomedical research, What is ME? What is CFS? Information for Clinicians & Lawyers and ME and CFS, the Definitions, Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC SCIENCE! and Redefinitions of ME - a 20th Century Phenomenon.](#) Many more articles on all aspects of M.E. are available in the [Myalgic Encephalomyelitis research and articles.](#) See also [Section 2;](#) [Section 3;](#) and [Section 4;](#) of the database for links to more of the best political and medical overviews of M.E.
- This misdiagnosis of ‘CFS’ and lack of appropriate medical treatment can have many negative effects on this heterogeneous group of patients. For example, there have been cases where cancer sufferers suffering severe fatigue (as is common in cancer) have been misdiagnosed as ‘CFS’ and subsequently died due to lack of treatment. Dr Byron Hyde’s paper [The Complexities of Diagnosis](#) mentions several such cases (as well as many other issues and case studies of CFS misdiagnosis).
- How is the public affected by the denials and propaganda surrounding M.E.? In a number of ways, for example, see [What is Myalgic Encephalomyelitis? Extra extended version](#) for information on how the government’s pretence of ignorance has impacted on the transmission of M.E.
- M.E. is a distinct neurological illness which has a well-documented and unique set of characteristics, symptoms, physical signs and diagnostic (and other) abnormalities which may be tested for. Contrary to popular belief, M.E. is a distinct, recognisable entity that can be diagnosed relatively early

in the course of the disease, providing the physician has some experience with the illness. The new Nightingale Definition of M.E. created by the worlds leading M.E. expert Dr Byron Hyde also makes diagnosis easier than ever before even for those with no prior experience in diagnosing M.E. This is a pure M.E. definition and, most importantly, it is a TESTABLE M.E. definition. For an explanation of some of the issues of M.E. diagnosis in more detail see: Testing for Myalgic Encephalomyelitis. Again, see Testing for M.E. for a discussion of the benefits and limitations of the Canadian ‘ME/CFS’ criteria.

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

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

*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. Thus while it is important to be aware of the small amount of research findings that do hold some value for M.E. patients, using the term ‘ICD-CFS’ to refer to this research is misleading and in many ways just damaging as using terms and concepts like ‘ME/CFS’ or ‘CFS/ME.’

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

## and 'ICD-CFS'

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

- 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.* For more information see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [The Terminology Explained](#) and [What is Myalgic Encephalomyelitis?](#) and [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.](#) In short:

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

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

- See also: Problems with 'our' M.E. (or 'CFS' 'CFIDS' or 'ME/CFS' etc.) advocacy groups (also available in an animated video format) and the new paper: M.E. vs MS: Similarities and differences
- 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.

## 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. For more information and for a full list of references see the References page.

“People in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of

the persecuted, when they too come up against a wall of utter indifference.’  
Professor Hooper 2003

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

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

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

There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion. Dr Elizabeth Dowsett

Psychiatric treatment is very useful and essential for psychiatric patients. Primary M.E. patients are simply not psychiatric patients. Unfortunately, it is not only psychiatrist physicians that have made themselves the tools of insurance companies. Dr Byron Hyde 2006

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

With the rapid development of technology and access to international publication, the UK retained its reputation as a leading centre of M.E. research and remained able to report clinical studies backed up by molecular biology, brain imaging, sophisticated hormonal and other biochemical studies. At this point, with sound evidence of an infective cause, the way in which such infection is spread and the pathogenesis of the disease, why were we urged to adopt the "fatigue definitions" inflicted upon M.E. sufferers by USA scientists? Redefinitions of M.E. - a 20th Century Phenomenon by Dr Elizabeth Dowsett

Professor Malcolm Hooper explains that 'Wessely school' psychiatrists, and those who follow them, have: 'Built their careers and reputations on denying the physical nature of M.E., with the result that untold numbers of chronically and seriously ill patients are bullied, derided, threatened and driven to suicide by being told that they are not physically ill but are suffering from "aberrant illness beliefs"'. WesselySchool psychiatrists have been described in the eBMJ (N Portman, 3<sup>rd</sup> December 2003) as "*a small clique of undemocratic, unaccountable, self-serving psychiatrists who have managed to monopolise most of the research funding in this field and, thanks to their prejudices, have been its downfall ever since.*" Without doubt, the influence of Simon Wessely has resulted in a cascade of horrors which most people do not know about and when they do, they find scarcely believable.'

Myalgic Encephalomyelitis is not depression. Myalgic Encephalomyelitis is not hysteria. Myalgic Encephalomyelitis is not a conversion disorder nor is it a somatization disorder. Myalgic Encephalomyelitis is an acute onset diffuse injury of the brain. Psychiatrists should not ever be placed in charge of diagnosis and treatment of M.E. patients. It is simply not their area of expertise and their meddling has at times caused great harm to M.E. patients. Also, during the 20 years that I have investigated M.E. patients I have yet to see a single case of real M.E. that has responded to psychiatric pharmacological treatment. 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

The invention of Chronic Fatigue Syndrome has to be one of the most curious cases of inventive American scientific imperialism that one could imagine. Dr Byron Hyde 2006

The body, its systems (such as the gastrointestinal system, the muscular system, the endocrine system, the cardiovascular and vascular systems) and its organs are dependent and their actions largely controlled by the brain. If the brain is physiologically injured, then so is the body. Depending upon which parts of the brain are physiologically injured different parts of the body will also be caused to malfunction. Dr Byron Hyde 2006

On the lack of funding given to legitimate M.E. research, Dr Byron Hyde M.D. writes: Without heed, we are sitting on the edge of a cliff, waiting for disaster. For many sufferers of M.E. that disaster is already here, and few are listening. Dr Hyde in The Clinical and Scientific Basis of ME p. 115

Since Professor Cheney has shown that in M.E. patients, cardiac output struggles to meet metabolic demand, how can forced aerobic exercise help such patients remain as functional as possible? In the light of the Peckerman et al paper that was published in 2003, are the psychiatrists and their peer reviewers at the MRC who approved the PACE trial protocol still convinced that these trials (and the exercise regimes to be meted out by the new Centres) pose no harm for those with M.E.? Perhaps they are content to rely on the certainty that they themselves can never be held accountable for any harm to any patient because all participants must sign a compulsory waiver which means that no participant can ever pursue any claim for medical negligence or damages? M. Williams.

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

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

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

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

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Taken from [www.hfme.org](http://www.hfme.org)



- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were ‘atypical multiple sclerosis’ and ‘atypical polio.’
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation’s International Classification of Diseases since 1969 as a distinct organic neurological disease with the ICD code G.93.3.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

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

However, the hearts of M.E. patients only pump barely 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.