THE CBT & GET DATABASE

A HFME GUIDE

A comprehensive guide to the inappropriate and harmful use of CBT and GET on patients with Myalgic Encephalomyelitis sourced from the world's leading M.E. experts.

Myalgic Encephalomyelitis is primarily a neurological illness. It is classified as such under the WHO international classification of diseases, although non-neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. **Dr Elizabeth Dowsett**

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%. The brain, muscles and peripheral circulation are placed in physiological difficulty. **Byron Hyde MD**

M.E. has a UNIQUE neuro-hormonal profile. Prompt recognition and advice to avoid overexertion is mandatory. **Dr Elizabeth Dowsett & Dr Melvin Ramsay**

M.E. is a clearly defined disease process. M.E. is a serious (acute-onset) diffuse brain injury and appears to be in the same family of diseases as polio and MS. This relationship is the reason that Gilliam, in his analysis of the L.A. M.E. epidemic in 1934, called M.E. 'atypical poliomyelitis.' **Byron Hyde MD**

Jodi Bassett

(& The Hummingbirds' Foundation for M.E. team)

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.

CBT and GET database – Condensed version

Taken from www.hfme.org

The **CBT and GET Database** is a stand-alone comprehensive guide to the use of CBT and GET on patients with Myalgic Encephalomyelitis and the psychiatric or 'behavioural' paradigm of M.E. generally.

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.

The full-length 100 page + resource is aimed at lawyers, politicians, media, the friends and family of sufferers - but primarily at those clinicians who choose to recommend CBT and GET to their patients. It is hoped that these doctors will read something here that will forever change their minds on this subject and so benefit their patients, themselves and society generally.

This text is a condensed version of the database.

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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.

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 an 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 Coxsackie infected [enterovirus infected] mice, forced to swim to the point of exhaustion during the acute phase of infection, developed chronic heart disease whereas Coxsackie 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, aberrent 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 current 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.**

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

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 homoeostasis (The brain can no longer receive, store or act upon information which enables it to control vital body functions, cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance, appreciation of space, shape etc). It has an UNIQUE Neuro-hormonal profile. Dr Elizabeth Dowsett

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 pathogenisis 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, 3rd 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

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

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.

- 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.

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2: Recommended background reading

A brief overview of the historical and political facts of Myalgic Encephalomyelitis was given in the introductory text: Smoke and Mirrors

For those who would like more information the following texts are highly recommended. They each provide good overviews of the major medical and political facts of M.E., and/or the history of M.E.

For historical, political and medical overviews of M.E. see:

- What is Myalgic Encephalomyelitis? A medical and political overview of the illness which also includes links to many more relevant articles and books for further reading. An excerpt of this text is reproduced below.
- Putting Myalgic Encephalomyelitis research and articles into context Because of the politics and financial interests involved in M.E. research it is vitally important that before you read anything about the illness that you read this paper first and understand the context in which it was written.
- Testing for Myalgic Encephalomyelitis A basic overview of some of the series of tests which can be done to help confirm a suspected M.E. diagnosis (also contains further information on many other aspects of diagnosis).
- The ultra-comprehensive Myalgic Encephalomyelitis symptom list.
- Treating Myalgic Encephalomyelitis - avoiding overexertion
- The myths about Myalgic Encephalomyelitis
- Why the disease category of 'CFS' must be abandoned M.E. and 'CFS' are not the same. This paper discusses why renaming, refining or sub-grouping 'CFS' cannot work and why 'CFS' must be abandoned.
- The misdiagnosis of CFS None of the definitions of CFS defines M.E., so what do they define? What does a diagnosis of 'CFS' actually mean?
- M.E. vs MS: Similarities and differences M.E. and MS are very similar diseases medically in many ways. However, for reasons that have nothing to do with science, the two diseases are treated very differently politically and socially. The contrast could not be more stark. M.E. patients are treated terribly (and often abused terribly, even unto death in some cases), yet there is no public outcry as there would be if MS patients were treated in this same way. Thus people with M.E. find themselves in the terrible position of actually ENVYING people who have MS.
- Who benefits from 'CFS' and 'ME/CFS'? 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 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? This paper looks at all of these very important questions.
- This website has become so large that its features can no longer all be taken in at a glance. In order for site visitors to find the information they need more quickly, this page features Information Guides relevant to each of the different types of visitors to the site.

See also:

- The Nightingale Definition of M.E. and A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis & An Irreverent History of Chronic Fatigue Syndrome and The Complexities of Diagnosis and Are Myalgic Encephalomyelitis and CFS Synonymous Terms? by Byron Hyde MD
- Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC SCIENCE! and The Late Effects Of M.E. and A Rose by Any Other Name and Redefinitions of ME - a 20th Century Phenomenon by Dr Elizabeth Dowsett

- What is ME? What is CFS? Information for Clinicians & Lawyers by Eileen Marshall, Margaret Williams & Professor Malcolm Hooper
- Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research and The Mental Health Movement: Persecution of Patients? by Professor Malcolm Hooper
- Worldwide Epidemic:an ALERT to citizens worldwide and; ME and CFS, the Definitions from The Committee for Justice and Recognition of Myalgic Encephalomyelitis
- How to disguise a disease by Cesar Quintero

For a list of purely medical overviews of Myalgic Encephalomyelitis see **Section 4** of this guide.

Individual research papers

Hundreds of individual research abstracts and articles by some of the world's leading M.E. experts and authors are also available to view; search for articles by topic or by author.

See: Myalgic Encephalomyelitis research and articles

This is a collection of literally HUNDREDS of some of the best research and articles, from some of the worlds leading researchers, doctors and M.E. advocates. Sections include: M.E. outbreaks, M.E. and children, viral research, cardiac research, the severity of M.E. and many more.

Essential reading on M.E. The book: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Edited by Byron Hyde, M.D. is also vital reading for anyone with a real interest in M.E.

This book provides, in one superb 75-chapter source, an up-to-date, comprehensive account of current knowledge concerning the history, epidemiology, children with M.E., investigation, virology, immunology, muscle pathology, host response, food intolerance, brain mapping, neurophysiology, neuropsychology, psychiatry, sleep dysfunction and much more. This is an essential reference book for medical, government and public library reference rooms. This text is a unique vehicle for researchers, physicians and other health education and government officials, and is also easily understandable by the general public. All funds from the sale of this book go towards M.E. research and advocacy. See the Review of this book for more information and for purchasing details.

The following books are also highly recommended:

- CFS: A Treatment Guide by Verillo and Gellman.
- Stricken: Voices from the Hidden Epidemic of CFIDS edited by Peggy Munson
- Osler's Web by Hillary Johnson
- Skewed: Psychiatric Hegemony and the Manufacture of Mental Illness in MCS, GWS, ME and CFS by Martin J Walker
- Engaging with M.E. and What is ME? What is CFS? by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams

See the Book Reviews section for more information about these (and many other) M.E. books.

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A warning on 'CFS' and 'ME/CFS' research and advocacy

 Written by Jodi Bassett and co-written by Lesley Ben, April 2009. This version updated May 2009. Taken from www.hfme.org

The various definitions of 'CFS' *do not* define M.E. Myalgic Encephalomyelitis is an organic neurological disorder; 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.

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 many other diseases. The question for M.E. patients is whether any of the research on 'CFS' may be relevant to them/their disease

The overwhelming majority of research on 'CFS' or 'CFIDS' or 'ME/CFS' or 'CFS/ME' or 'ICD-CFS' does not involve M.E. patients and is not relevant *in any way* to M.E. patients. (For discussion of 'ICD-CFS,' see 'What does the term ICD-CFS mean?') These terms and concepts are often used to describe all those patients with Lyme disease, various post-viral fatigue syndromes, burnout, adrenal exhaustion, depression and so on. These terms and concepts are meaningless and are used to refer to very different, and often very mixed, patient groups.

Research which may involve M.E.

Whether influenced by political considerations surrounding the name/definition 'CFS' or not, however, some researchers have produced a very small amount of research under the name 'CFS' which involves at least some M.E. patients, as this research details those abnormalities which are unique to M.E.

It is important to be aware of the research findings that do hold some value for M.E. patients, although it may be difficult to distinguish these from valueless 'CFS' research. A very 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.

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

.

The issues discussed here apply not only to research, but also to politics, advocacy and discussion; a very small amount of what is done in the name of 'CFS' or 'CFIDS' or 'ME/CFS' may be relevant to M.E. Most of it is not relevant to M.E. and may severely harm the interests of M.E. patients (and other patients misdiagnosed with 'CFS').

Assessing 'CFS' research: a checklist

List of characteristics associated with M.E. (suggesting that the research is, to some extent, studying M.E.):

- Acute onset (associated with a virus; an enterovirus)
- The disease occurs in outbreaks as well as sporadically (the incubation period of the virus is 4-7 days)
- Damage to the central nervous system (which is observable on brain scans, and which is similar to MS)
- Consequences of neurological damage such as loss of homeostasis in many of the body's systems
- Abnormalities seen on many different objective tests (including ESR tests, NK cells tests, Holter monitors and physical exam) within weeks of disease onset
- Seizures and paralysis
- Cognitive dysfunction, involving concentration, memory and perceptual problems
- Sensory disturbance and over-sensitivity
- Reduced circulating blood volume and associated problems such as orthostatic intolerance, neurally mediated hypotension and POTS
- Cardiac abnormalities such as tachycardia and reduced cardiac function

- Mitochondrial dysfunction, resulting in loss of energy production, and impaired immunity and cellular repair capability
- Immune dysfunction
- Delayed effect following physical, mental or sensory overexertion (24 to 72 hours or more)
- Worsening of illness, serious relapse or possibly death following overexertion
- Severe disability lasting many years (most often lifelong) which may also result in death

Modern M.E. research tallies closely with historical M.E. research and data from the world's most experienced M.E. experts such as Dr Ramsay, Dr Richardson, Dr Dowsett and Dr Hyde.

Research/advocacy articles by Dr Ramsay, Dr Richardson, Dr Dowsett and Dr Hyde are highly recommended. Medical information by Dr Cheney is most likely of interest, although Dr Cheney cannot be described as a M.E. expert as he unfortunately mixes the facts about M.E. and 'CFS' in his work. (See: Is Cheney talking about M.E. or 'CFS'? and also MERGE/MERUK, 'ME/CFS' and 'CFS.')

List of characteristics associated with 'CFS' (indicating that the research is looking at mixed 'CFS' patient groups and is useless for M.E. patients):

- Gradual onset
- Onset following overwork or stress
- Onset following EBV infection (or other common viruses including flu, Ross River virus, hepatitis infections and so on)
- Fatigue or exhaustion (as the defining or most severe symptom of the illness) or symptoms referred to as vague and 'everyday' type symptoms
- Omission of the serious neurological and cardiac (and other) dysfunctions which define M.E.
- Emotional state, personality type or psychological history associated with causing or prolonging illness
- Short duration of illness and/or naturally resolving illness after a short period of time or illness which resolves or improves with exercise therapy, psychotherapy or antidepressant drugs (or similar)
- Mild illness which cannot result in death

Research which discusses subtypes, subsets or subcategories of 'CFS' or 'CFS/ME' or 'ME/CFS' etc. is not relevant to M.E. These so-called subgroups merely define different groups of patients misdiagnosed with 'CFS' or 'ME/CFS.' These are not M.E. patients; they are patients who urgently need to be given their correct diagnosis of Lyme disease, Candida, MCSS, PTSD, depression, and so on.

Articles which support concepts such as renaming 'CFS' as 'ME/CFS' (or similar) are also unhelpful, not relevant to M.E. and should not be considered a genuine contribution to M.E. activism. This strategy benefits only the same vested interest groups which benefitted from the creation of 'CFS.' (See: Who benefits from 'CFS' and 'ME/CFS'? and Problems with the so-called "Fair name" campaign.)

Unfortunately, while many advocacy groups started out doing excellent work to improve things for M.E. sufferers, today this is no longer true in most cases. Very nearly all of these groups which started out determined to fight against the bogus 'CFS' propaganda and the abuse of science and ethics, are now actively SUPPORTING it. They have sold patients out to the highest bidder. Thus information provided by almost all so-called advocacy groups in this field should not be trusted or assumed in any way to be useful or accurate or in the best interests of patients. This particularly applies to information given by AfME and the MEA in the UK, the two largest CFIDS groups in the US, and each of the state 'CFS/ME' or 'ME/CFS' societies in Australia, for example. For more information see: Problems with 'our' M.E. (or 'CFS' 'CFIDS' or 'ME/CFS' etc.) advocacy groups, Problems with the so-called "Fair name" campaign, On the current (worrying) state of Australian 'CFS/ME' societies and M.E. advocacy and 'CFS' advocacy are not the same.)

Research which is funded by the NIH or CDC in the US or the MRC in the UK is virtually always irrelevant to M.E. The same applies to research involving Wessely, Sharpe, Cleare, Aylward, White, members of the Nijmegen group, Lloyd, Hickie, and their colleagues and collaborators. (See: Who benefits from 'CFS' and 'ME/CFS'?)

Problems with this heterogeneous and skewed research

A very small number of 'CFS' studies refer in part to people with M.E. but it is not always 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. Virtually all of the 'CFS' or 'ICD-CFS' or 'ME/CFS' research which does relate to M.E. (at least in part) is also significantly contaminated by 'CFS' propaganda.

Note that if the various 'CFS' criteria are strictly followed, those patients with the neurological disease M.E. (who will always exhibit unambiguous signs of organic disease) will be excluded from study as 'CFS' describes a syndrome which is always 'medically unexplained.'

Often the research that offers a glimmer of genuine hope to Myalgic Encephalomyelitis patients is research into diseases that share significant similarities with M.E. including Alzheimer's, Polio, Parkinson's, AIDS, Lupus, Multiple Sclerosis and so on. (Alzheimer's, Parkinson's and Multiple Sclerosis are listed along with M.E. under 'Diseases of the nervous system' in the ICD Classifications.) These studies have far more relevance to M.E. patients than almost all of the 'CFS' studies produced which lack scientific merit and use exclusively or almost exclusively non-M.E. patient groups.

Why not reject all 'CFS' research?

It may be tempting for people who understand this situation to reject/ignore all work on/discussion of 'CFS' altogether, as not being relevant to M.E. However, a blanket rejection of all parts of all 'CFS' research could be just as dangerous as a blanket acceptance of all bogus 'CFS' research. Some 'CFS' labelled research does undoubtedly involve M.E. patients and does describe those abnormalities/characteristics unique to M.E. patients, and so may be of use to M.E. patients in search of practical help.

If the M.E. community were to reject all 'CFS' labelled research as 'only relating to 'CFS' patients' (including research which describes those abnormalities/characteristics unique to M.E. patients), this would seem to support the myth that 'CFS' is just a somewhat 'watered down' definition of M.E. and that M.E. and 'CFS' are virtually the same thing and share many characteristics. This is the number one myth that causes so much confusion and leads to so much abuse and needless extra suffering and deaths. The M.E. community cannot afford to give any support to this myth, lest we further entrench our own abuse (and the abuse and neglect of all those misdiagnosed with 'CFS' who do not have M.E.).

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. The bogus disease category of 'CFS' must be abandoned for the benefit of M.E. patients and all other patient groups involved. The M.E. community must work uncompromisingly towards these goals.

More information

- Note that virtually all of the research which does relate to M.E. (at least in part) but which uses the term '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' and imply that M.E. and 'CFS' represented one and the same patient group. For information on some of the most common inaccuracies and 'CFS' misinformation included in (to some extent) M.E. relevant research, see the paper: Putting research and articles on into context

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

- Note that whether or not a study or activism article is relevant to M.E. cannot unfortunately be determined by examining terminology alone as the terminology of M.E. and 'CFS' etc. is often used interchangeably, incorrectly and confusingly.

- Although the terminology is often used interchangeably, incorrectly and confusingly, the DEFINITIONS of M.E. and 'CFS' are very different and distinct. It is the definitions of each of these terms which are of primary importance. *The distinction must be made between terminology and definitions.*

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

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 – is Myalgic Encephalomyelitis. M.E. is not synonymous with CFS, nor is it a subgroup of CFS. (There is no such disease/s as "CFS.') To read a referenced version of this text, see: What is M.E.?

- 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 What is M.E.?
- For further details of the WHO ICD classifications of M.E. and 'CFS' worldwide (and why terms such as 'ICD-CFS' and 'ME/CFS' must be avoided) please see the paper by Lesley Ben entitled: The World Health Organization's International Classification of Diseases (WHO ICD), ME, 'CFS,' 'ME/CFS' and 'ICD-CFS.'
- M.E. is similar in a number of significant ways to multiple sclerosis, Lupus and poliomyelitis (polio). See the new paper: M.E. vs MS: Similarities and differences
- Those patients (mis)diagnosed with 'CFS' (and who do not have M.E.) are advised to read the following papers: The Misdiagnosis of 'CFS' and Where to after a 'CFS' (mis)diagnosis?
- 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 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. For more information see the References page.

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

M.E. is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction which causes a breakdown in bodily homoeostasis. It has an UNIQUE Neuro-hormonal profile. .Dr Elizabeth Dowsett

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

"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

3: Research and articles

Research and articles 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.

Before reading this research/advocacy information, please be aware of the following facts:
1. Myalgic Encephalomyelitis and 'Chronic Fatigue Syndrome' are not synonymous terms. The overwhelming majority of research on 'CFS' or 'CFIDS' or 'ME/CFS' or 'CFS/ME' or 'ICD-CFS' does not involve M.E. patients and is not relevant *in any way* to M.E. patients. If the M.E. community were to reject all 'CFS' labelled research as 'only relating to 'CFS' patients' (including research which describes those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that 'CFS' is just a 'watered down' definition of M.E. and that M.E. and 'CFS' are virtually the same thing and share many characteristics.

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

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

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

Myalgic encephalomyelitis--a persistent enteroviral infection? Dowsett EG, Ramsay AM, McCartney RA, Bell EJ. Basildon Hospital, Essex, UK. 1990

Myalgic encephalomyelitis is a common disability but frequently misinterpreted. Amongst 6,000 patients referred for general microbiological diagnosis between 1975 and 1987, 420 cases were recognized. This illness is distinguished from a variety of other post-viral states by an unique clinical and epidemiological pattern characteristic of enteroviral infection. Prompt recognition and advice to avoid over-exertion is mandatory.

MYALGIC ENCEPHALOMYELITIS : A Baffling Syndrome With a Tragic Aftermath. By A. Melvin Ramsay M.D., Hon Consultant Physician, Infectious Diseases Dept, Royal Free Hospital. [Published 1986]

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 and this was illustrated by the aforementioned three patients admitted to hospital in an unconscious state; all three recovered completely. 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.

SEVERELY AFFECTED ME (MYALGIC ENCEPHALOMYELITIS) ANALYSIS REPORT ON QUESTIONNAIRE (Word document)Analysis Report by 25% ME Group, 1st March 2004

Graded exercise therapy: 95% found it unhelpful
Cognitive behavioural therapy: 93% found it unhelpful

By far the most unhelpful form of treatment was considered to be Graded Exercise Therapy (GET). This is a finding that may surprise some readers, given the current medical popularity of this approach. However, these patients' perceptions are supported by data from previous experience: of the 39% of our members who had actually used Graded Exercise Therapy, a shocking 82**%** reported that their condition was made worse by this treatment. On the basis of our members' experiences we question whether GET is an appropriate approach for patients with ME. It is worth noting that some patients were **not severely affected before trying GET**. Thus, it is not only people with severe ME who may be adversely affected by this form of treatment.

Comments from the Canadian Guidelines on Cognitive Behavior Therapy (CBT) and Graded Exercise Therapy (GET) This excerpt is taken from pages 46-49 of the article "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols" which appeared in the Journal of Chronic Fatigue Syndrome, Vol. 11(1) 2003, pp. 7-115, by Carruthers et al

Two hypotheses have been presented as underlying the CBT model of chronic fatigue syndrome (105). The first hypothesis "assumes that the pathophysiology of CFS is largely irreversible, but considers that a fine-tuning of the patient's understanding and coping behavior may achieve some improvement in his or her quality of life." The second hypothesis is based on the premise that the patient's impairments are learned due to wrong thinking, and "considers the pathophysiology of CFS to be entirely reversible and perpetuated only by the interaction of cognition, behavior, and emotional processes. According to this model, CBT should not only improve the quality of the patient's life, but could be potentially curative" (105).

There is much that is objectionable in the very value-laden second hypothesis, with its implied primary causal role of cognitive, behavioral and emotional processes in the genesis of ME/CFS. This hypothesis is far from being confirmed, either on the basis of research findings or from its empirical results.

Nevertheless, the assumption of its truth by some has been used to influence attitudes and decisions within the medical community and the general cultural and social milieu of ME/CFS. To ignore the demonstrated biological pathology of this illness, to disregard the patient's autonomy and experience and tell them to ignore their symptoms, all too often leads to blaming patients for their illness and withholding medical support and treatment.

Care must be taken not to classify patients experiencing chronic fatigue as ME/CFS patients unless they meet all the criteria for ME/CFS, as the outcomes for these two patient groups are substantially different.

A well informed physician empowers the patient by respecting their experiences, counsels the patients in coping strategies, and helps them achieve optimal exercise and activity levels within their limits in a common sense, non-ideological manner, which is not tied to deadlines or other hidden agenda.

[To understand more about the context of the Canadian Definition (and its limitations), see: A review of the 2003 ME/CFS clinical case definition Note that this is not a M.E. definition, but a mix of facts relating to M.E. and 'CFS' unfortunately.]

SOME FACTS AND FIGURES ON CBT, GET AND OTHER APPROACHES Directly from the 'Horses' Mouths: by Doris M Jones MSc.

In July 1998 the then Chief Medical Officer, Sir Kenneth Calman, announced the setting up of a Working Group on CFS/ME, to include patients, carers, patient group representatives as well as medical experts, including Psychiatrists. Over 80 people took part in this 3 year exercise, including myself. Eventually details were available on 3074 patients, and the summarized results showed very clearly that:

1. **The most helpful strategies were:**

a) Pacing activity with rest (2300/2568 cases = 90%)
b) Bed rest (2165/2426 cases = 89%)
c) Dietary changes (1496/2226 cases = 67%)
2. **The least effective strategy was:** CBT
3. **The most harmful strategy was:** Graded exercise

It was psychiatrists who could not accept these findings and as a group walked out, refusing to endorse or sign what was already a much 'toned-down' final draft report.

Surely it is time that psychiatrists took some notice and actually listened to what patients tell them. I have yet to come across a patient who complains about any treatment which works, whether this is allopathic, psychological methods (like CBT) or exercise regimes (like Graded Exercises). If it works, no-one will complain; the problem is these approaches very often don't, and this is the one and only reason why patients are so persistent in their demands for other options and are determined to get to the real causes of their ill health. Psychiatrists have made things worse for many, in more ways than one.

CRITICAL CONSIDERATIONS by Margaret Williams, 1st November 2004

'The issue is whether or not compulsory exercise regimes and "rehabilitative programmes" may be harmful to those with ME / CFS. Significantly, there is now further supportive evidence that has emerged from the 7th AACFS International Conference held in Madison, Wisconsin, from 8-10th October 2004: "**An analysis of metabolic features using MRSI (magnetic resonance spectroscopy imaging) showed elevated lactate levels, which suggests mitochondrial metabolic dysfunction similar to mitochondrial encephalomyopathy**"**.**

Given this evidence, how can forced aerobic exercise be beneficial to such patients? Will the MRC trial participants be screened for such abnormalities before taking part in the aerobic exercise regimes that are the basis of the trial?

There is also evidence that many people with ME / CFS may have a serious heart problem. In April 2003, Arnold Peckerman MD from New Jersey reported findings to the annual meeting of the American Physiological Society that demonstrated via a sophisticated test that after exercise, the heart of those with ME / CFS pumped less blood than it did at rest. Peckerman is on record as saying: "Basically we are talking about heart failure. Chronic fatigue syndrome is a progressive disease". Cardiologist Joseph Miller MD from Emory University agrees that these patients have serious heart problems.

What are the risks of forcing such patients to undertake aerobic exercise regimes and "push themselves back to fitness"? The ME community will recall the case of Brynmor John MP who had ME but who was advised to exercise back to fitness; he dutifully tried to do so but collapsed and died coming out of the House of Commons gym.'

Clarification about CRITICAL CONSIDERATIONS by Margaret Williams, 2nd November 2004

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 by Dr Byron Hyde

'Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. Though CFS is based upon a typical M.E. epidemic, in my opinion it has always been a confused and distorted view of reality. The invention of Chronic Fatigue Syndrome has to be one of the most curious cases of inventive American scientific imperialism that one could imagine. It is my opinion that 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.'

The Complexities of Diagnosis by Byron Hyde MD

The physician and patient alike should remember that CFS is *not* a disease. It is a chronic fatigue state as described in four definitions starting with that published by Dr. Gary Holmes of the CDC and others in 1988 (Holmes, Kaplan, Gantz, et al., 1988; Holmes, Kaplan, Schonberger, et .al., 1988). The definition created by Lloyd, Hickie, Boughton, Spencer, and Wakefield (1990) is also widely used in Australia. There are two

subsequent definitions. The Oxford definition of 1991 (Sharpe et al., 1991) and the 1994 NIH/CDC definitions (Fukuda et al., 1994) are basically, with a few modifications, copies of the first definition. Where the one essential characteristic of ME is acquired CNS dysfunction, that of CFS is primarily chronic fatigue. By assumption, this CFS fatigue can be acquired abruptly or gradually. Secondary symptoms and signs were then added to this primary fatigue anomaly. None of these secondary symptoms is individually essential for the definition and few are scientifically testable. Despite the list of signs and symptoms and test exclusions in these definitions, patients who conform to any of these four CFS definitions may still have an undiagnosed major illness, certain of which are potentially treatable.

New Labour, the market state, and the end of welfare by Jonathan Rutherford: Jonathan Rutherford looks at the connections between government and the insurance business in their joint project to reduce eligibility for sickness benefits.

'Unum's 1995 'Chronic Fatigue Syndrome Management Plan' sounded the alarm: 'Unum stands to lose millions if we do not move quickly to address this increasing problem'.

It was actually Provident that was quickest off the mark, introducing an aggressive system of 'claims management' that would become the industry norm. It could not influence interest rates, but it could reduce the number of successful claims it paid out. Its Independent Medical Examination (IM.E.) was skewed in favour of the company through the work undertaken by its claims adjusters and in-house doctors. Illnesses were characterised as 'self-reported' and so thrown into question. Only 'objective' test results were accepted. Some disabling conditions were labelled as 'psychological', which made them ineligible for insurance cover beyond 24 months. Doctors were pressured to use the 'subjective nature' of 'mental' and 'nervous' claims to the company's advantage. Specific illnesses were targeted in order to discredit the legitimacy of claims. The industry drew on the work of two of the Woodstock conference participants, Professor Simon Wessely of King's College and Professor Michael Sharpe of Edinburgh University, in an attempt to reclassify [M.E.] as a psychiatric disorder. Success would allow payouts to be restricted to the 24 month limit for psychological claims and save millions of dollars. By 1997 Provident had restructured its organisation to focus on disability income insurance as its main business. It acquired Paul Revere, and then in 1999 merged with Unum under the name UnumProvident.

Meanwhile, in the US UnumProvident's business activities had been coming under increasing scrutiny. In 2003, the Insurance Commissioner of the State of California announced that the three big insurance companies had been conducting their business fraudulently. As a matter of ordinary practice and custom they had compelled claimants to either accept less than the amount due under the terms of the policies or resort to litigation. The following year a multistate review identified four areas of concern: an excessive reliance on in-house professionals; unfair construction of doctor's or IME reports; a failure to properly evaluate the totality of the claimants' medical condition; and an inappropriate burden on the claimant to justify eligibility for benefit. UnumProvident was forced to reopen hundreds of thousands of rejected insurance claims. Commissioner John Garamendi described UnumProvident as 'an outlaw company': 'It is a company that for years has operated in an illegal fashion.''

"In November 2001 a conference assembled at Woodstock, near Oxford. Its subject was 'Malingering and Illness Deception'. Amongst the 39 academics and experts was Malcolm Wicks, Parliamentary Under Secretary of State for Work, and Mansel Aylward, his Chief Medical Officer at the Department of Work and Pensions (DWP). What linked many of the participants together, including Aylward, was their association with the giant US income protection company UnumProvident".

"New Labour was looking to transform the welfare system".

"In 1994 Peter Lilley, (Conservative) Secretary of State for Social Security, hired John LoCascio to advise on 'claims management'. Lo Cascio was second vice president of Unum. He joined the 'medical evaluation group'. Another key figure in the group was Mansel Aylward. They devised a stringent All Work Test. Approved doctors were trained in Unum's approach to claims management".

"(Unum)Provident introduced an aggressive system of 'claims management'.

"Specific illnesses were targeted in order to discredit the legitimacy of claims".

"In the UK, two Woodstock participants, Professor Simon Wessely and Professor Michael Sharpe, were working on reclassifying ME/CFS as a psychiatric disorder. A change in classification would save the industry millions of dollars".

"(In) 1999 New Labour introduced the Welfare Reform Act. Mansel Aylward devised a new Personal Capability Assessment (PCA). The task of administering the PCA was contracted out to SchlumbergerSema which was then taken over (along with its DWP assets) by the US corporation Atos Origin. Its computerised evaluation of claims resulted in significant numbers of rejected claims".

"In July 2004 (UnumProvident) opened its £1.6 million UnumProvident Centre for Psychosocial and Disability Research at Cardiff University. The company appointed Mansel Ayward as Director following his retirement from the DWP. Professor Peter Halligan, who had forged the partnership with UnumProvident, was ambitious: 'Within the next five years, the work will hopefully facilitate a significant re-orientation in current medical practise in the UK' ".

"The two men were joined by Gordon Waddell, another Woodstock participant. In 2005 the centre produced The Scientific and Conceptual Basis of Incapacity Benefits (TSO, 2005) written by Waddell and Aylward and published by the DWP. The methodology used by Waddell and Aylward is the same one that informs the work of UnumProvident".

"In a memorandum submitted to the House of Commons Select Committee on Work and Pensions, UnumProvident define their method of working: '**Our extended experience has shown us that the correct model to apply when helping people return to work is a bio-psychosocial one' ".**

"Waddell and Aylward adopt the same argument. Disease is the only objective, medically diagnosable pathology. Sickness is a temporary phenomenon. **Illness is a behaviour**".

"(Incapacity benefit) trends are a social cultural phenomenon, rather than a health problem".

"The solution is not to cure the sick, but a 'fundamental transformation in the way society deals with sickness and disabilities' (page 123)".

"The goal and outcome of treatment is work".

"No-one who is ill should have a straightforward right to Incapacity Benefit".

"(In the US in 2004) Commissioner John Garamendi described UnumProvident as 'an outlaw company. It is a company that for years has operated in an illegal fashion' ".

"The (UK) 2006 Welfare Reform Bill sets a target of an 80 per cent employment rate. To achieve this, the numbers on Incapacity Benefit will have to be reduced by one million. In 2008, Incapacity Benefit will be replaced by an Employment and Support Allowance. 'Customers' who fail to participate in work-focused interviews or to engage in work related activity will lose benefits".

What is ME? What is CFS? Information for Clinicians & Lawyers Eileen Marshall, Margaret Williams & Professor Malcolm Hooper, 2001

'Despite all this verifiable and authenticated international research, much of the current perception of ME, both medical and lay, is beset by confusion and misinformation. **There are still doctors who dismiss the condition as non-existent and too many sick children are still being forcibly removed from their parents and placed in institutional care where they are forced to undergo inappropriate exercise regimes under the care of psychiatrists.**

Refusal by some doctors to accept what is known about ME /ICD-CFS may raise the question of whether or not such doctors are in breach of their contract of employment if that contract requires them to keep abreast of advancing medical knowledge. Guidance issued by the General Medical Council (GMC) requires that doctors *"must observe and keep up to date with the laws and statutory codes of practice which affect your work."* **(105)** The fact that so many doctors do not keep reasonably up-to-date about ME / ICD-CFS has enormous implications for patients. **(106)**

Wessely leads a group of UK doctors, mostly but not exclusively psychiatrists, who have colloquially become known as the " Wessely School". Apart from those mentioned, there are other areas related to ME / ICD-CFS in which Wessely is known to have special [vested] interests, none of which he usually declares. Wessely himself

has published over 200 papers mostly on his own view of CFS but his beliefs are not supported by international experts and there is stringent criticism of his papers in the peer-reviewed medical literature (see below). The whole area of terminology has become a minefield for the unwary, to the serious detriment of patients.'

Cognitive behavioural therapy for ME/CFS sufferers: How strong is the evidence? ME Research UK, The Gateway, Perth; and the Department of Medicine, University of Dundee

'The evidence for the routine use of CBT for ME/CFS patients is sparse, and does not justify many of the claims made for this intervention. Conclusions about efficacy must be tentative given the paucity of trials; the relatively small number of patients involved; the problems inherent in comparing CBT, which included a graded exercise component in both trials, with control interventions, such as relaxation or group support; and, importantly, the potential effect of publication bias. Sir — Judith Prins and colleagues' report (1) leaves the clear impression that there is a powerful case for the provision of CBT as a specific therapy for CFS. However, careful assessment of published studies suggests that this impression is not evidence-based.'

PUPPETS, PUPPETEERS, POLITICIANS AND RACKETEERS by Gurli Bagnall

But where does all this leave those who suffer ME, GWS and other "poorly understood" conditions? We live in an environment of secrecy; of a public being misled; of blatant lies and criminal behaviour covered up with the approval of governments. Where does the buck stop? Who are the people who are making fortunes out of contrived diseases?

It is not hard to understand why Claire Wilson was chosen to interview Simon Wessely for the New Scientist recently — it certainly cannot have been for her journalistic abilities. At least 99.9% of us were brought up to respect the medical profession. The letters after the name were enough to ensure the figurative bowing and scraping that was demanded no matter how incompetent or how lacking some were as doctors and human beings.

A medical career afforded and affords sadists the opportunity to abuse their powers and no matter how gross their behaviour, the support has rarely been for the victim — the patient. How ever illogical and unintelligent the doctor; how ever flawed his diagnosis and treatment, he was never questioned. He did as he pleased and was accountable to no one. If a doctor said it, then it must be so and his word was law.

Then along came Simon Wessely. Where in history has a western doctor engendered such public anger and dislike as has he and by extension, his followers? There has to be a reason yet journalist, Claire Wilson, who interviewed Wessely on behalf of the New Scientist, did not challenge his contention that the hate mail he CLAIMS to receive, goes with the territory. Such public abhorrence does not go with the territory and never has. It seems the editor of the New Scientist has his own place in the ranks of the puppet brigade.

The ME community in the UK was particularly hard hit when the Countess of Mar, long time champion of the cause in the House of Lords, switched sides. The organizers of the recent conference in the US talked of exciting progress with a diagnostic test just around the next corner. All were encouraged to make a donation to the planned research.

When it became apparent that CBT was included in these "exciting" developments with what appeared to be an endorsement from Nancy Klimas, I put my papers away. Too many puppets…too many puppeteers.

Inadequacy of the York (2005) Systematic Review of the CFS/ME Medical Evidence Base. Comment on Section 3 of The diagnosis, treatment and management of chronic fatigue syndrome (CFS)/(ME) in adults and children Work to support the NICE Guidelines October 2005. Comment by Professor Malcolm Hooper & Horace Reid, January 2006

'There is evidence that some UK CFS researchers exhibit bias, in exaggerating the beneficial effects of their treatments. It is useful to note the way some British CFS/ME clinicians tailor their comments to cater for different audiences. When presenting their findings to a British audience, they claim "substantial" - almost curative - benefits. However in the American forum the same individuals will say that the benefits are only "modest", and "not a panacea".

Wessely in the UK. *"substantial improvements in measures of fatigue and physical functioning.*"[25]
Wessely in the USA. *"modestly effective"; "neither approach is remotely curative*"; *"not the answer to CFS*".[26]
Sharpe in the UK. *"the overall treatment effect was substantial"; "a return to normal functioning (albeit often with continuing fatigue) is possible in most cases*".[27]
Sharpe in the USA. *"CBT is not a panacea"* [28]

In America they face more robust peer review from heavyweight rivals, and are more circumspect in their claims. A number of leading US researchers are sceptical of their claimed results, in any case. **Key Message: UK research on CBT & GET may suffer from bias. NICE should not take it findings at face value.'**

The Mental Health Movement: Persecution of Patients? by Professor Malcolm Hooper, 2003
Full title: A CONSIDERATION OF THE ROLE OF PROFESSOR SIMON WESSELY AND OTHER MEMBERS OF THE "WESSELY SCHOOL" IN THE PERCEPTION OF MYALGIC ENCEPHALOMYELITIS (ME) IN THE UK

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.

In the UK, patients with myalgic encephalomyelitis (ME, also known as Chronic Fatigue Syndrome or CFS), particularly children, have suffered gross and barbaric abuse and persistent denigration as a consequence of the beliefs of certain psychiatrists who are attempting to control the national agenda for this complex and severe neuro-immunological disorder.

These psychiatrists are shown to be clearly in breach of the first tenet of medicine --- first do no harm--- in that by their words and deeds they have wreaked havoc in the lives of ME/ICD-CFS patients and their families by their arrogant pursuit of a psychiatric construct of the disorder which ignores the abundant clinical and scientific evidence (widely presented in the international medical and scientific literature) of the organic nature of ME/ICD-CFS

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. As a consequence, Government funding into the biomedical aspects of the disorder is non-existent

This coterie of psychiatrists has proven affiliations with corporate industry and has insidiously infiltrated all the major institutions, directing funding for research into an exclusively psychiatric model of the disorder, focusing on "management strategies" involving psychiatric techniques, even though such techniques have been shown to be at best of no lasting value and at worst to be harmful to patients with ME/ICD-CFS.

Mobility problems in ME by Dr Elizabeth Dowsett

The symptoms of this multi system disease are characterised by post encephalitic damage to the brain stem [(1)] (which contains major nerve centres controlling bodily homeostais) and through which many spinal nerve tracts connect with higher centres in the brain. Some individuals have, in addition, damage to skeletal and heart muscle. SPECIFIC MOBILITY PROBLEMS INCLUDE THE FOLLOWING:

NEUROLOGICAL PROBLEMS.

a. Exhaustion, weakness and collapse following mental or physical exertion beyond the patents' capacity. This arises from metabolic damage. Whereas in healthy controls or in other illnesses (such as depression) there is an increased metabolic response to exertion, in ME this is diminished, leading to sudden collapse which requires several days or more for recovery. These complications (following even trivial exercise) are not recognised in short medical examinations for social benefits and no allowance is made for the delayed effects of exertion.
b. Recent research indicates that these patients have high *resting* energy requirements which further diminish their resources.
c. Problems with balance are common in ME due to involvement of spinal nerve tracts in the damaged brain stem.

MUSCULO-SKELETAL PROBLEMS

a. Over 70% of ME patients suffer from significant bone and muscle pain (due to disordered sensory perception – a further consequence of brain stem damage which seriously affects their mobility).

b. Other patients have (in addition) metabolic damage to muscle fibres resulting in abnormal early lactic acidosis as demonstrated by sub anaerobic exercise tests.

c. 30% of patients with abnormal exercise tests have evidence of persistent infection in the muscle and of muscle infarcts (tender points on pressure affecting mainly limb and trunk muscles) and of jitter (due to incoordinated muscle fibre action) on slow leg raising for example, following damage to the neuromuscular junction. A rapid decline in thigh muscle tone can be demonstrated between 2 and 24 hours after exercise [3.]

CARDIOVASCULAR PROBLEMS

Patients with ME suffer a variety of symptoms arising from autonomic nervous system dysfunction [4.] including liability to a dangerous drop in blood pressure on standing for more than a few minutes, while some 20% have progressive and frequently undiagnosed degeneration of cardiac muscle **which has led, in several cases, to sudden death following exercise.**

Politically-modified Research Eileen Marshall and Margaret WIlliams, 26th June 2005

'If only someone with sufficient influence would question where "Wessely School" psychiatrists get their opinions from. If this were to happen, then the rampant metastatic spread of their unproven beliefs would soon stop because their opinions are not -- and cannot be -- based on biomedical evidence. But then, "policy-based evidence" is not required to be based on biomedical evidence and that, of course, is its value to Government.'

Profits Before Patients? Eileen Marshall and Margaret Williams, 15th April 2005

The role of the Medical Research Council (MRC) is to fund projects on the basis of expertly written, peer-reviewed and approved proposals. Clearly, therefore, the role of peer-reviewers is of paramount importance as it is they who influence what research the MRC will fund. In the case of ME/ICD-CFS there are a limited number of peer-reviewers of psychiatric interventions of cognitive behavioural therapy and graded exercise apart from the PACE trial proponents themselves, so the favourable recommendation of the carefully selected peer-reviewers was not unexpected, nor was the decision to fund the trials on "CFS/ME" patients. The PACE trials involve compulsory aerobic exercise even though the deleterious effects of such exercise on those with ME/ICD-CFS are well documented in the medical literature.

Considering the rapidly increasing weight of available published data on organic pathology in ME/ICD-CFS (little of which is published in the UK medical literature), the MRC will inevitably have its hand forced eventually, as the time will come when such evidence can no longer continue to be ignored, but currently this seems to remain a forlorn hope. Surely this is a short-sighted policy, because it is well recognised that those who are correctly diagnosed and permitted to rest adequately in the initial stages are the ones who have hope of some recovery; moreover, if relevant research were to be instituted, it would lead to patients being investigated competently and treated correctly, thus offering the prospect of ME/ICD-CFS patients being able to return to an economically productive life.

Question marks over evidential basis of claims for psychosocial therapies ME Research UK, The Gateway, Perth; and the Department of Medicine, University of Dundee

'Methods and Results: In response to an article in the British Medical Journal, we reviewed trials of the use of psychosocial therapies in ME/CFS. The total number of available trials is small, numbers are relatively low (6/8 trials have n<40 in the active groups), and 2 of the 5 cognitive behavioural therapy (CBT) trials do not show an overall significant effect. No trial contains a "control" intervention adequate to determine specific "efficacy": in only 2 trials are the treatment arms compared with an "active", though not indistinguishable, intervention. A number of non-specific effects could have accounted for the positive results, and the fact that the drop-out rate in the active arm of one of the trials was 40% may point in this direction, as discussed in one of the reviews. Again, the heterogeneity of the trials, the potential effect of publication or funding bias for which there is some evidence, and professional doubts about the evidence base for some behavioural therapies themselves give grounds for caution.

Abbot NC, Newton DJ
Letter to the British Medical Journal 2002
Sharpe and Wilks' review [1] contains an "evidence-based summary" with the statement, "graded exercise and cognitive behavioural therapies are effective in treating chronic fatigue syndrome". However, rigorous

examination of the literature indicates that this remark is not itself evidence-based, a serious criticism since evidence-based summaries in the BMJ carry weight and are widely quoted.

Again, the heterogeneity of the trials, the potential effect of publication or funding bias for which there is some evidence [4], and professional doubts about the evidence base for some behavioural therapies themselves [5] give grounds for caution. Indeed, if a similar evidence base existed for, say, Shamanic healing - which has no professional proponents - it would arouse little clinical interest.

Neither of the review groups has commended GET or CBT as particularly effective for chronic fatigue syndrome patients. Whiting et al. [2] state, "all conclusions about effectiveness should be considered together with the methodological inadequacies of the studies."

Physiological responses to incremental exercise in patients with chronic fatigue syndrome. Inbar O, Dlin R, Rotstein A, Whipp BJ.

'As a group, the CFS patients demonstrated significantly lower cardiovascular as well as ventilatory values at peak exercise, compared with the control group.' 'These results could indicate either cardiac or peripheral insufficiency embedded in the pathology of CFS patients.' 'We conclude that indexes from cardiopulmonary exercise testing may be used as objective discriminatory indicators for evaluation of patients.'

House of Lords Debate Thursday, 22 January 2004

The Countess of Mar rose to ask Her Majesty's Government whether they subscribe to the World Health Organisation international classification of diseases for myalgic encephalomyelitis (ME) under ICD 10.G93.3- neurological disorders. 'Since 1992, one of the terms listed in the ICD as an alternative for ME is chronic fatigue syndrome. It is that term that is now used by international researchers and which has given rise to the confusing terms of ME/CFS and CFS/ME, a confusion that has served well the aims of a group of psychiatrists who assert that, whatever term is used, ME/CFS is simply medically unexplained chronic fatigue and that it should be classified as a mental disorder over which they should exert control.

Since his arrival on the scene in 1987, Wessely has repeatedly and persistently played down, dismissed, trivialised or ignored most of the significant international biomedical evidence of organic pathology found in ME because it does not fit his psychiatric model of the disorder, for which he claims to have developed a more intensive form of the psychiatric intervention known as cognitive behaviour therapy (CBT). That consists of using intensive, mind-altering techniques to convince patients that they do not suffer from a physical illness. It also includes forced regimes of graded exercise to be supervised by a Wessely school-trained psychotherapist aimed at getting patients back to fitness.

Wessely school psychiatrists are about to receive £11.1 million, including £2.6 million from the Medical Research Council, in an attempt to strengthen the weak evidence that his regime actually works for those with ME. Among his largely undeclared, interests it should be noted that he is a member of the supervisory board of a company, PRISMA, that is supplying such rehabilitation programmes as CBT to the NHS for those with ME, even though such regimes have been widely shown, at their best, to be of limited and short-lasting benefit and, more importantly, at their worst, to be actively harmful to those with the disorder.

Chronic fatigue syndrome: assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise. Jammes Y, Steinberg JG, Mambrini O, Bregeon F, Delliaux S

'The response of CFS patients to incremental exercise associates a lengthened and accentuated oxidative stress together with marked alterations of the muscle membrane excitability. These two objective signs of muscle dysfunction are sufficient to explain muscle pain and postexertional malaise reported by our patients.'

CONCERNS ABOUT A COMMERCIAL CONFLICT OF INTEREST UNDERLYING THE DWP HANDBOOK ENTRY ON MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME
(THE GIBSON PARLIAMENTARY INQUIRY) Professor Malcolm Hooper, Eileen Marshall and Margaret Williams, December 2005

The information in this document is relevant to the Gibson Inquiry, specifically the continued ignoring by the Department of Work and Pensions (DWP) and its commercial advisers of the compelling scientific evidence that myalgic encephalomyelitis / chronic fatigue syndrome is not a primary psychiatric disorder. If eligibility for

certain benefits becomes contingent upon the intended implementation of compulsory psychiatric "rehabilitation" regimes, in cases of authentic ME/CFS it is likely to result in serious relapse that may be life-long (and may in some cases even result in death)

Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC SCIENCE! by Dr Elizabeth Dowsett

WHAT IS RESEARCH? It is simply an attempt to discover the truth. However, even in 1999, this search may still concentrate on one of 2 alternate pathways:

a) The METAPHYSICAL (or philosophical) route which seeks to establish truth purely by reason and argument.

b) The PHYSICAL (or scientific) path which sets out to determine facts by systematic investigation of material events and by experiment.

The metaphysical approach bears much the same relationship to the scientific as ASTROLOGY (which involves the influence of the stars on human affairs) does to ASTROPHYSICS (which determines the chemical and physical composition of astral bodies).

Although research funding for the study of ME is minimal in the UK, the major sources (totalling some £5 million in recent years) are non governmental agencies such as the Pharmaceutical and other industries. The major beneficiaries are, without doubt, members of the psychiatric profession who have exhumed ancient terms such as "hysteria" and invented new ones such as "somatisation" to explain that patients suffering from ME perpetuate their own illness. Previously reputable medical journals concur with this strange philosophy(11.)

In the mid 1980's, the incidence of ME had increased by some seven times in Canada and the UK, while in the USA a major outbreak at Lake Tahoe (wrongly ascribed at first to a herpes virus) led to calls for a new name and new definition for the disease, more descriptive of herpes infection. This definition based on "fatigue"**(10.)** (a symptom common to hundreds of diseases and to normal life, but not a distinguishing feature of myalgic encephalomyelitis) was designed to facilitate research funded by the manufacturers of new anti-herpes drugs. However, a "fatigue" definition (which also omits any reference to children) has proved disastrous for research in the current decade. Whether in its original form or in the 4 redefinitions which have followed, most research workers, led by the Americans are now calling for an urgent change (omitting "fatigue") so that like can be compared with like in international ME research.

Unanswered Questions: do inconsistencies matter in medicine? By Margaret Williams, 10th September 2005

Following recent posts about the intention of members of the Wessely School / One-Health company to persuade Government agencies to implement a national programme of cognitive behavioural therapy and graded exercise regimes for those with alleged "behavioural" disorders in which they include "CFS/ME" (see Co-Cure ACT: "Proof Positive?": 2nd September 2005 and "More Proof Positive?": 4th September 2005), there are numerous inconsistencies that seem to remain unaddressed by One-Health company lobbyists. They include (i) the irrationality of drawing conclusions across differing patient populations (for example, lumping together those with primary psychiatric disorder and those with primary organic disorder and then claiming that this amalgamation represents one single "behavioural" disorder); (ii) the absurdity of relying on assumptions as the basis for a compulsory management regime (for example, that ME/CFS patients obtain secondary gain); (iii) the divergent assertions about the efficacy of cognitive behavioural therapy; (iv) the inherent danger of applying a "one-size fits all" management policy to those with "CFS/ME" and (v) the opposing evidence of these psychiatrists' intention to claim "CFS/ME" as a psychiatric disorder.

Alterations in muscles of CFS patients at morphological, biochemical and molecular level. Pizzigallo E, Di Girolamo A, Montanari G, Dragani L, Vecchiet J, Calella G.

'Our results agree with those of other AA (Behan et al., 1991; Gow et al., 1994). The alterations are compatible with a myopathy of probable mitochondrial origin. This could explain the drop in the functional capability of the muscle as a reduction in potency but, above all, as a reduction in resistance. In conclusion, even if CFS seems to be attributable to mitochondrial and/or muscular alterations, a damage in the central nervous system cannot be excluded. This could explain the neurophychological, behavioral, and neuroendocrinological alterations often found in these patients.

The Model of the Myth? Eileen Marshall and Margaret Williams, 17th March 2006

Perhaps Professor Peter White (editor of "Biopsychosocial Medicine: An integrated approach to understanding illness" [OUP 2005] who is currently principal investigator in the Medical Research Council PACE trials of this model) -- as well as other Wessely School members -- are unaware that the model they so fervently espouse is based not on a legitimate model by Engel after all, but simply on a myth? (For information on White's book, see "Proof Positive?" on Co-Cure ACT: 2nd September 2005).

The ME community may like to know that McLaren presented a paper entitled "The biopsychosocial model and scientific fraud" at the annual congress of RANZCP in May 2004, which is available from the author at Northern Psychiatric Services, Darwin, Northern Territory, Australia.

The papers by Susanna Agardy referred to in the paper above, are available at the links below:

DOES GRADED EXERCISE THERAPY IMPROVE POST-EXERTIONAL MALAISE IN CFS?

'People with CFS/ME are being increasingly urged to exercise to improve functioning. In the same editorial the problem of post-exertional malaise is acknowledged: 'the cardinal phenomenon of fatigue in CFS is characterised by a marked and prolonged exacerbation of symptoms following minor physical activity'[1]. As CFS/ME people with this problem know, this exacerbation is often delayed and brings into play many symptoms. This should be enough to indicate that there is something extraordinary, rather than just exacerbated fatigue happening here. To what extent can the results of these studies be generalised to people with post-exertional malaise?'

Susanna Agardy's letter to Chris Clark

'You might also ask, in the interest of clear unambiguous research, how they get the positive results for CFS/ME people in GET studies. You could ask why the Oxford Criteria are repeatedly are used for selection of subjects, when these criteria do not even include 'post-exertional malaise', that is, exercise intolerance, the distinguishing feature of CFS/ME. The use of the Oxford Criteria and of the ambiguous CDC criteria in exercise studies invites an unknown number of the subjects to participate, who very likely have idiopathic fatigue or something else. The results are then passed off as applying to ME/CFS people and widely imposed on us. The conclusions of these flawed studies acquire the status of self-evident truth by merely being repeated uncritically, ad infinitum. The PACE study, using the same inappropriate criteria, seems to be expected to put the cream on the cake and to confirm what is already held to be the truth.'

More on the Myth? by Eileen Marshall and Margaret Williams, 21st March 2006

What can explain the delusion that prevents certain psychiatrists from engaging with reality? Despite the significant evidence that destroys their misconceptions and shows their beliefs about ME/CFS to be wrong, Wessely School psychiatrists persist in their belief that it is a behavioural disorder that they believe is synonymous with "neurasthenia" and they continue tenaciously in their efforts to get ME/CFS re-classified as a mental disorder. Evidence-based reality seems entirely lost on this group of psychiatrists.

(Note: If the "biopsychosocial" approach worked and did not result in serious relapse, and if the biological factors were "largely reversible", there would be no long-term sufferers from ME/CFS because patients are desperate to regain their health and independence. The GMC recently criticised and struck off a doctor for practising outside his area of expertise. If psychiatrists attempt to claim dominion over " a wide range of disorders", they might be at similar risk because it is not possible for them to be experts in such complex fields as vascular biology or gene expression that are known to be disrupted in ME/CFS. Wessely himself stated at his Gresham College lecture on 25th January 2006 that he did not understand immunology).

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Exercise capacity and immune function in male and female patients with chronic fatigue syndrome (CFS). Snell CR, Vanness JM, Strayer DR, Stevens SR.

'A significant multivariate main effect was found for immune status ($p < 0.01$), with no gender effect or interaction. Follow-up analyses identified VO2(peak) as contributing most to the difference. These results implicate abnormal immune activity in the pathology of exercise intolerance in CFS and are consistent with a channelopathy involving oxidative stress and nitric oxide-related toxicity.'

Is Stress more than a modern buzz word? by Dr Elizabeth Dowsett

"The major disadvantage of this illness is not a medical one but relates to a social climate of opinion in the media and medical press, which ascribes this serious neurological disability to some type of "personality disorder" rather than to underlying organic causes, of which we now have overwhelming research evidence. While this monstrous distortion of the facts blames the patient for deliberately causing and maintaining the illness, it conveniently absolves the statutory caring agencies from caring."

'Response to cognitive behaviour therapy -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.'

Differences between ME & CFS by Dr Elizabeth Dowsett

"There are actually 30 well documented causes of 'chronic fatigue'. To say that ME is a 'subset' of CFS is just as ridiculous as to say it is a 'subset' of diabetes or Japanese B encephalitis or one of the manifestly absurd psychiatric diagnosis, such as, 'personality disorder' or 'somatisation'.

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

Consideration of Some Issues Relating to the Published Views of Psychiatrists of the "Wessely School" in relation to their belief about the nature, cause and treatment of myalgic encephalomyelitis (ME), 2000

[Contains excellent information about Simon Wessely]

'It should be noted that there is no evidence of maladaptive beliefs, nor of phobic avoidance of activity in patients with ME. In contrast to claims made by the "Wessely School", other more rigorously controlled studies have found low rates of depression. Longitudinal studies using appropriate measures have shown that patients' attributions to a physical cause do not affect outcome; moreover, research on patients with ME indicate that a belief in a biological cause is not associated with poor mental health. There has been no study assessing the effectiveness of graded exercise or cognitive behavioural therapy in ME or in strictly-defined CFS. .

'As long ago as 1988, young people with ME were being subjected to psychiatric "distraction therapy"; the most well-known case is that of Ean Proctor from the Isle of Man, then a twelve year old boy who, against his parents' wishes and with no prior warning, was forcibly taken from his parents. A policeman was standing by and a Court Order had been obtained (which was supported - in writing-by Wessely). Before being referred to doctors in London, Ean had been subjected to terrifying ordeals: his local doctors did not believe in ME so they devised activities which were designed to prove that the child's symptoms were simulated. One such "distraction therapy" involved taking the petrified child on a ghost train in the expectation that he would cry out in fear on 3rd June 1988 Wessely had written a letter saying that Ean's inability to speak was " elective mutism")."

Psychiatrists of the "Wessely School" seem to think that the standard of evidence required is different in the discipline of psychiatry: for example, they always quote extensive reference papers in supposed support of their published articles but with this particular group of psychiatrists, the impartiality of the references they cite needs to be scrutinised, because these psychiatrists often name just the lead author and perhaps two or three others and then write "et al". This is customary practice when listing medical references, but with this group, it conceals the fact that they are often simply citing themselves and their own papers. It used to be the case that editors of medical journals would permit no more than two or three self-references for an article. Seemingly, executive editors now make no stipulation about the number of self-references permitted, which automatically opens the door for bias and bad science and for those who are unashamedly self-promoters.'

Which Interventions are Helpful to Patients with 'CFS/ME'? A REVIEW OF THE EVIDENCE

Those who seek to respond appropriately to the needs of patients presenting with a diagnosis of 'Chronic Fatigue Syndrome' [CFS] – whether policy makers at political level, service planners, or providers on the ground – should be aware that evidence for the efficacy of behavioural interventions (graded exercise/activity and cognitive behavioural therapy [CBT]) is contradictory and by no means conclusive. *(see pages 5-13)*

"Much of the current thinking about CFS and M.E. is driven by models of deconditioning. … But what if exercise results in a huge delivery of free radicals, not because of disuse of muscle and deconditioning, but because there is something organically wrong with muscle metabolism? What value exercise in these circumstances? These are crucial questions, and it is important to remember that the current evidence [sic] for deconditioning is not based on scientific investigations of muscle but on suppositions about patients with 'fatigue'." [58]

"**By far the most unhelpful form of treatment was considered to be Graded Exercise Therapy (GET).** This finding may surprise some readers, given the current medical popularity of this approach. However, these patients' perceptions are supported by data from previous experience: of the 39% of our members who had actually used Graded Exercise Therapy, a shocking 82% reported that their condition was made worse by this treatment. On the basis of our members' experiences we question whether GET is an appropriate approach for patients with ME. It is worth noting that some patients were **not severely affected before trying GET**. Thus, it is not only people with severe ME who may be adversely affected by this form of treatment."

Exercise Capacity in Chronic Fatigue Syndrome Pascale De Becker, PhD; Johan Roeykens, PT; Masha Reynders, PT; Neil McGregor, MD, PhD;

'This study clearly shows that patients with CFS are limited in their physical capacities. Based on the American Medical Association Guidelines for Impairment Rating,[51] our 55.2% of patients who had a VO_2max of less than 20 mL/kg per minute correspond to class 3-4 on the disability scale, indicating moderate to severe impairment.[51],

'CFS can and does result in prolonged debilitation.[3, 4, 51],

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Chronic fatigue syndrome Neil C Abbot (a,b) and Vance Spence (a) The Lancet 2006; 367:1574

The overwhelming focus of the Seminar is on one model of chronic fatigue syndrome-the biopsychosocial model, a construct which contrasts with the biomedical model which implies that a primary disease entity exists and that biopsychosocial aspects are secondary (the two models discussed in the report to the UK Chief Medical Officer in 2002 [3]. The biopsychosocial model is supported only by researchers with a professional interest in psychosocial aspects of illness who have acquired the funding to test their hypotheses.

Assessment and Treatment of Patients with ME/CFS: Clinical Guidelines for Psychiatrists by Eleanor Stein MD FRCP(C)*[see notes on this text below]

If ME/CFS were a psychiatric disorder, one would expect psychological symptoms to predict outcome. However this is not the case. Studies consistently show that symptom severity at onset and whether one meets full criteria for CFS [ie. Myalgic Encephalomyelitis] predict prognosis in ME/CFS (Darbishire *et al*, 2005) but psychological symptoms and cognitive beliefs do not (Deale *et al*, 1998;Jones *et al*, 2004a). (Darbishire *et al*, 2005;White *et al*, 1998)

'Although Cognitive Behavior Therapy (CBT) is widely recommended for patients with ME/CFS, it is far from clear whether cognitive behavior therapy is helpful for most patients. CBT to convince a patient that s/he does not have a physical disorder is disrespectful and inappropriate.'

Despite the fact that worsening of symptoms after exercise is a compulsory criteria for diagnosis of ME/CFS, graded exercise programs have often prescribed for such patients. Presumably these recommendations are made on the assumption that exercise will be accompanied by improved aerobic capacity, increased anaerobic threshold and improved exercise tolerance. However, in patients with ME/CFS, neither exercise tolerance nor fitness has been shown to improve with exercise programs.

[*Note: This article is tentatively included as it contains some very good factual information on the lack of evidence and uselessness of CBT and GET and the psychological approach in general in M.E. patients. However, perhaps due to the author's area of expertise, parts of it also (in complete contradiction) greatly overstate the need

for psychiatric intervention and involvement in M.E. treatment and diagnosis; ideas not supported by this website, nor the existing literature and biomedical research on M.E. In other words, much of the information on this paper relates to 'CFS' rather than M.E.]

Redefinitions of ME - a 20th Century Phenomenon by Dr Elizabeth Dowsett

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

Repetitively negative changing T waves at 24-h electrocardiographic monitors in patients with the chronic fatigue syndrome - left ventricular dysfunction in a cohort. Lerner AM, Lawrie C, Dworkin HS. Chest 1993; 104(5): 1417-21.

'The patients with CFS all had abnormal Holter readings' 'All 60 patients with CFS showed repetitively flat to inverted T waves alternating with normal T waves.'

AN INTOLERABLE OBSCENITY by Gurli Bagnall, 21 March 2005

The job description for Trainee Clinical Fatigue Therapists in some of the new network of 12 Fatigue Clinics across England, was the last straw. While the language used was not unexpected, to see it in black and white was nevertheless a body blow to those who suffer Myalgic Encephalomyelitis as defined by the WHO, for it is at them that the proposed "services" are aimed.

The Pros and Cons of ME clinics by Gurli Bagnall, 27 July 2006

'What life saving strategies do the clinics have? How do the Clinics deal with heart failure or any organ failure for that matter? How many will die of such failures, or cancers or despair -induced suicides while undergoing a course of Cognitive Behavioural Therapy and psychotropic drugs? In whom should we have faith. "Seize this opportunity," Ms. Adcock urges. What opportunity? From my hospital-type bed and motorized wheel chair, I don't see the new clinics presenting any opportunity at all.'

OPEN LETTER TO MS. AUDREY ADCOCK by Gurli Bagnall, 28 July 2006

Exciting New Direction? (Do they think we are nuts?) by Gurli Bagnall, May 2008

I refer to the Fair Name Campaign Update - Exciting New Direction, written by Rich Carson. I would like to pass a couple of short comments. When this Fair name campaign first raised its head, the manner in which it did so, left me thinking, "They're trying to tell grandma how to suck eggs!"

Here were a bunch of strangers telling people who have endured ME for years - even decades - what to do and how to do it. Today, 21 May 2008, they are still pushing that same barrow - a very similar barrow to the one that Wessely and others (in the UK) have been pushing since the 1980s. We know the moves; we know the tactics. We could give Rich lessons if he wants.... After thinking for awhile, I managed to get off my bed and onto the motorized wheelchair without which, I go nowhere - even in the house - and I headed for my computer.

This update, reminded me of James Jones (if I remember the name correctly) who is a colleague of Rich and Cort. Readers might recall that Jones entertained us with his version of the definitions of sickness, illness and disease. He maintained that people can be sick and ill at the same time, but not diseased. On the other hand, they can be diseased and ill, but not sick! Yet again they can...

Mr. Jones was clearly excited about this topic and went on at considerable length with many convoluted explanations. The feeling I got was that he desperately WANTED to say something, but really he had nothing relevant to say! What a shame! How very sad! If he had just given it some thought, he would have realized that there are none so diseased as those who suffer a terminal illness; a point I raised at the time.

It was clear to me these people had an agenda which has nothing to do with fairness for the sufferers. In fact if they ARE speaking about an actual disease, that disease is not ME. What makes me so sure of that, is something Rich said. Quote:

"First, and most importantly, the patient community has jumped on board. Your feedback has been positive and encouraging."

Say honey chil'! Haven't yo' been readin' letters on the internet lately? Seems to me no one was jumpin' about anywhere! There sure as heck weren't no GET goin' on in ma neck of the woods. Even ma wheelchair won't do no wheelies no mo'.

Seriously, folks, I am sure Rich et al. don't really think we are a bunch of numbskulls to be manipulated and treated with contempt. I feel sure their hearts are in the right places and probably have some disorder or other in mind. But it is NOT ME and before they go any further, they really need to get the basics right; sort out their illnesses, sicknesses and diseases and then start afresh towards wherever they thought they were heading in the first place. Who knows....Alice might give them a guided tour of the rabbit hole!

Some time ago, erikmoldwarrior posted a quotation which I think is relevant at this time. I have copied it out below and thank Erik for drawing it to our attention:

"A nation can survive its fools, and even the ambitious. But it cannot survive treason from within.

An enemy at the gate is less formidable, for he is known and he carries his banner openly.

But the traitor moves among those within the gate freely, his sly whispers rustling through all the alleys, heard in the very halls of government itself.

For the traitor appears [as] not [a] traitor - he speaks in the accents familiar to his victims; and he wears their face and their garments, and he appeals to the baseness that lies deep in the hears of all men.

He rots the soul of a nation - he works secretly and unknown in the night to undermine the pillars of a city - he infects the body politic so that it can no longer resist. A murderer is less to be feared. "

Cicero, Roman philosopher and statesman, 42 BC

To put it another way: With friends like these, who needs enemies? (Author unknown.)

WHEN WILL THEY EVER LEARN? by Gurli Bagnall

Those who favour CFS/ME or ME/CFS seem to be under the impression that Myalgic Encephalomyelitis sufferers will be delighted to accept this compromise. But we have already lived with that particular compromise for some years and we are still 'kindly' being told that this choice describes the disease the best.

For goodness sake! This is a serious matter. It is not a child's game! We do not live with Alice in her Wonderland. We live in the real world where the name of a disease influences impressionable members of the medical profession to the point where their prejudices turn to outright abuses.

Having seen and experienced the disastrous effect CFS had and has upon our lives, we now hear that certain experts in the States have taken up the good fight for a "fair name". No wonder outsiders are often confused! The cool, calm and kindly manner of the "experts" is at odds with the patients' very apparent anger.

CONSPIRACIES AND BETRAYAL: Is NICE really nice? Gurli Bagnall, November 2008

Remember the wording used in the recruitment of "therapists" to administer CBT/GET at the CFS/ME clinics around the UK, and know that the main (figurative) requirement was a stout pair of jack-boots.

Conspiracy "theory"? The denials, rejections and silences surrounding the results of genuine research into the physical causes and effects of ME, are not theories. They are fact and without doubt, conspiracies.

How can the Countess justify her actions?

BREAKING A SILENCE By Gurli Bagnall

The subject of Dr. Rosamind Vallings[1] recent award has been in the headlines lately and no doubt she has helped many suffering from chronic fatigue or chronic fatigue syndrome as found in mental disorders.

Her own preference for the use of the terms CFS and 'encephalopathy' suggests that this is so. Myalgic encephalomyelitis, categorized by the
WHO as a neurological disease, is another matter entirely.

In the UK since the mid to late 1980s, the title of the condition went from ME to CFS to CF to CFS/ME and ME/CFS. No wonder people are confused. In this instance, confusion serves those who create it and the pharmaceutical industry well.

To say: 'I suffer ME - not CFS!' is difficult when relying upon the signature of an antagonistic doctor for the very right to exist. But unless we do, we will continue to suffer and die in this hell on earth that has quite deliberately, been created for us.

The Deified Doctor Syndrome (DDS) by Gurli Bagnall 2006

'Health is supposed to be the medical profession's business. Reason tells us that whatever is called for, be it drugs, acupuncture, herbs, supplements etc. the medical profession should be able to respond. Yet the statistics leave us in no doubt that instead of curing us, they are either killing us off, making us seriously ill or not making any difference at all.'

Muscle fibre characteristics and lactate responses to exercise in chronic fatigue syndrome Russell J M Lane,[a] Michael C Barrett,[b] David Woodrow,[b] Jill Moss,[b] Robert Fletcher,[b] Leonard C Archard[c a]

'Muscle histometry in patients with chronic fatigue syndrome generally did not show the changes expected as a result of inactivity. However, patients with abnormal lactate responses to exercise had a significantly lower proportion of mitochondria rich type 1 muscle fibres.'

Editorial: Our Conflicted Medical Journals
The New York Times, July 23, 2006

'Leading medical journals seem to be having a difficult time disentangling themselves from the pharmaceutical and medical device industries. If they cannot stop printing articles by scientists with close ties to these businesses, they should at least force the authors to disclose their conflicts of interest publicly so that doctors and patients are forewarned that the interpretations may be biased.'

[Bias in medical journals is an issue particularly relevant to M.E.]

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia:additional considerations for the MRC in relation to the PACE trials by Margaret Williams, 5th January 2005

For convenience, information already provided for the MRC PACE trial investigators about the most recognised differences between ME/CFS and FM is reproduced and summarised here:

In respect of the MRC CFS trials, there are known and established differences between FM and ME/CFS and many believe that the FM community and the ME/CFS community have a right to know why patients suffering from both disorders are to be amalgamated in the MRC trials that claim to be studying "CFS".

Likewise, an explanation is required as to why GPs are suddenly to be offered financial incentives to identify and refer people with FM to the new CFS centres specifically so that such patients can be entered into the MRC studies of "CFS".

UNUM Provident, Dr Mike Sharpe and Cognitive Behavioural Therapy: information which the MRC might wish to consider Eileen Marshall; Margaret Williams 12th April 2003

'Both the worldwide ME/CFS community and the MRC RAG on "CFS/ME" may be particularly surprised at Dr Michael Sharpe's evidence in Dr Morris' legal action. Sharpe, author of the article relied upon by UNUM, admitted that (quote) **"two subsequent controlled trials found cognitive behaviour therapy to offer no benefit over non-specific management"** (Exhibit #13-12).

Given that the MRC's RAG draft document on future research strategies for "CFS/ME" (compiled by Dr Chris Watkins, whose title is MRC Programme Manager for Research on Mental Illness and Drug Addiction) states at paragraph 166 that the direction of future management strategy in the UK should be CBT and graded exercise regimes, and that further research should "concentrate on the effects of these interventions across the spectrum of the disorder" (ie. on both the least severe and on the most severe cases), members of the MRC Research Advisory Group may now, in the light of Dr Sharpe's explicit evidence, wish to re-consider their preferred management strategies for this complex neuro-endocrine-immuno-vascular disorder. '

ME: WHY NO ACCOUNTABILITY? A synopsis for the UK Parliamentary Inquiry By Professor Malcolm Hooper and Margaret Williams, 18th August 2005

'ME is a multi-system disorder of extraordinarily incapacitating dimensions from which complete recovery is unlikely. It can be a devastating condition, with some patients being unable to speak or swallow and needing to be tube-fed for years; at least 25% of sufferers are severely affected, yet patients are accused of malingering. On the advice of Wessely School psychiatrists, state benefits are refused or withdrawn, even in cases of ME where they have been awarded for life. Many with ME commit suicide: in the UK, figures are said to run at one ME suicide per month. This is not because patients are psychiatrically ill: it is because they are completely unable to look after themselves and are too sick to survive without the necessary support, both medical and financial.'

Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research by Professor Hooper 2006

'Undoubtedly the perverse use of chronic fatigue syndrome, to impose a psychiatric definition for ME/CFS by allying it to fatigue syndromes, has delayed research, the discovery of effective treatment(s), and care and support for those suffering from this illness

I would propose that the use of CFS should now be abandoned and that, following the Minister of Health's assurances, the WHO definition is now accepted and used in all official documentations. The excellent work on the biological aspects of ME, already carried out by several leading research groups, now requires significant funding.'

FITTING THE PUZZLE TOGETHER by Gurli Bagnall 2009

"A new explanation was obviously called for, and without a by-your-leave, the typical successful career woman from the middle classes was scrapped in favour of a poorly educated person from a low socioeconomic background. Well….why not? If the label CFS is pinned to those presented as disenfranchised and vulnerable, who in authority, is going to argue?

CFS is not a diagnosis — it is an opinion. Those who promote it, create confusion with the clear intention of setting one group against another. Having created the mayhem, they sit back, feet up on the desk, hands behind the head, sucking on a fat corporate cigar while smugly saying, "Well….after all, what can you expect from hysterical people?"

Their arrogance and their confidence in themselves to manipulate the system reached the point some years ago where an attempt was made by stealth and deceit, to alter the WHO's International Classification of Diseases

(ICD) which lists ME as a neurological condition. To the lay person, this might seem like a criminal act but no one has ever been held accountable for this and other actions — a clear indication of the enormous wealth and power of the puppeteers who are pulling the strings behind the scenes.

Many of those who suffer Myalgic Encephalomyelitis (ME) are rightly adamant that whatever the above self-styled "experts" say, this condition bears no relationship to the group of psychiatric disorders that fall under the umbrella title of the politically contrived CFS."

IN ANGER by Gurli Bagnall 2009

"Similarly, the guidelines for the management of Myalgic Encephalomyelitis (ME) as decided by NICE are concerned with politics, not reality. That NICE has the support of the medical profession in general, the Judiciary, and certain members of parliament and the House of Lords, including Baroness Thornton, speaks for itself.

One would have hoped the authorities at this level would take responsible action; would lift the edges of the carpet to see what is hidden underneath; would be concerned about the reasons for the contention.

Instead, and as the Baroness has ably demonstrated, there are many in authority who have no experience or knowledge of ME; who do not have the intellectual acumen or who simply cannot be bothered to seek the answers. Adding to the dangers for those who suffer the condition, are the conflicts of interest amongst the law makers.

The following comments made by Baroness Thornton need special mention.

QUOTE:
"It goes so far as to say that healthcare professionals should recognise that the person with CFS/ME is in charge of the aims of the treatment programme."

COMMENT:
The Baroness is no doubt skilled in many areas, but expertise in the intricacies of entertaining does not offer experience is THIS field. Her statement is so out of touch it would be laughable if it were not so tragic."

ME Exists: True or False? by Eileen Marshall and Margaret Williams,18th August 2006

It seems that the powerful vested interests groups who now control the Establishment will tolerate no opposition, with the result that NHS doctors' freedom to practice medicine is increasingly proscribed.

With no hope of funding to establish a diagnostic test and with no will by the Royal Colleges or Government to formulate or accept an accurate case definition, the situation relating to ME/CFS in the UK cannot improve.

So many abnormalities have now been shown to occur regularly in cases of authentic ME/CFS 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.

4: A summary of the available medical research

What is known medically and scientifically about M.E. so far?
Despite popular opinion, Myalgic Encephalomyelitis is not 'medically unexplained' nor 'mysterious.' There simply is no legitimate scientifically motivated debate about whether or not M.E. is a 'real' illness or not or has a biological basis. The psychological or behavioural theories of M.E. are no more scientifically viable than are the theories of a 'flat earth.' They are pure fiction.

The reality is that there is an abundance of research which shows that M.E. is an organic illness which can have profound effects on many bodily systems and many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research articles; some dating back to the 1950s and earlier.

Myalgic Encephalomyelitis is not the same thing as 'CFS'
When the terms CFS, CFIDS, ME/CFS, CFS/ME, Myalgic Encephalopathy or ME-CFS are 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 patients.

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

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

There are now more than nine different definitions of 'CFS.' All each of these flawed CFS definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue. The fact that a person qualifies for a diagnosis of CFS, based on any of the CFS definitions (a) does not mean that the patient has Myalgic Encephalomyelitis, and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' A diagnosis of CFS – based on any of the CFS definitions – can only ever be a *mis*diagnosis.

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), for the benefit of all the patient groups involved. Myalgic Encephalomyelitis is a distinct neurological disease, it is not the same thing as 'CFS.'

What does the term ICD-CFS mean?

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

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

1) The main problem is that the term 'ICD-CFS' implies that 'CFS' has a WHO ICD classification as a neurological disease. 'CFS' has no ICD listing as a neurological disease. Indeed, in the version of the ICD in use in most of the world, 'CFS' has no classification at all. Myalgic Encephalomyelitis was classified as a distinct neurological disease in the WHO ICD in 1969 based on a large body of compelling scientific evidence. To imply that 'CFS' research and the definitions of 'CFS' have been properly evaluated by the WHO and classified as neurological is erroneous. Of course 'CFS' can never be classified as a neurological illness because none of the 'CFS' definitions define a neurological disease, or any distinct disease.

2) It is also erroneous to imply that the WHO has deemed 'CFS' to relate to Myalgic Encephalomyelitis in any way. The term ICD-CFS incorrectly suggests that 'CFS' and M.E. are synonymous terms for a single entity.

3) The term also implies a lack of scientific rigour in the ICD, suggesting that definitions as vague and as problematic as those of 'CFS' would be accepted by the WHO as the basis for a neurological classification. If this were to be believed, it would weaken the authority of Myalgic Encephalomyelitis's ICD classification.

4) In addition to its use in relation to research, some people use the term 'ICD-CFS' to refer to the disease generally. The term is usually used by people who are aware of the psychological paradigm of 'CFS,' and who want to indicate a real, biological disease rather than a psychological one. However, which exact disease or diseases are being referred to with this term varies considerably from one author to another. As with terms such as 'ME/CFS' the term 'ICD-CFS' only increases confusion as it has no agreed definition and many different groups use it to refer to very different, often very mixed, patient groups.

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

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

Myalgic Encephalomyelitis represents an acute change in the balance of neuropeptide messengers, and due to this, a resulting loss of the ability of the CNS (the brain) to adequately receive, interpret, store and recover information which enables it to control vital body functions (cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance etc). It is a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits.

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

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

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

All of this is not simply theory, but is based upon an enormous body of mutually supportive clinical information. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on.

What are some of the specific abnormalities that have been found in M.E. patients?
There is an abundance of research which shows that M.E. is an organic illness which can have profound effects on many bodily systems. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on. More than **a thousand** good articles now support the basic premises of M.E. Autopsies have also confirmed such reports of bodily damage and infection.

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

- there is evidence of disrupted biology at cell membrane level
- there is evidence of abnormal brain metabolism
- there is evidence of widespread cerebral hypoperfusion
- there is evidence of central nervous system immune dysfunction
- there is evidence of central nervous system inflammation and demyelination
- there is evidence of hypomyelination
- there is evidence that Myalgic Encephalomyelitis is a complex, serious multi-system autoimmune disorder (in Belgium, the disorder has now been placed between multiple sclerosis and Lupus)
- there is evidence of significant neutrophil apoptosis
- there is evidence that the immune system is chronically activated (eg. the CD4:CD8 ratio may be grossly elevated)

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

(Note that this is only a sample of some of the research available, not an exhaustive list.) It is known that Myalgic Encephalomyelitis is:

1. An acute onset (biphasic) epidemic or endemic infectious disease process
2. An autoimmune disease (with similarities to Lupus)
3. An infectious neurological disease, affecting adults and children
4. A disease which involves significant (and at times profound) cognitive impairment/dysfunction
5. A persistent viral infection (due to an enterovirus; the same type of virus which causes poliomyelitis and post-polio syndrome)
6. A diffuse and measurable injury to the vascular system of the central nervous system (the brain)
7. A central nervous system (CNS) disease (with similarities to MS)
8. A variable (but always, serious) diffuse (acquired) brain injury
9. A systemic illness (associated with organ pathology; particularly cardiac)
10. A vascular disease
11. A cardiovascular disease
12. A type of cardiac insufficiency
13. A mitochondrial disease
14. A metabolic disorder
15. A musculo-skeletal disorder
16. A neuroendocrine disease
17. A seizure disorder
18. A sleep disorder
19. A gastrointestinal disorder
20. A respiratory disorder
21. An allergic disorder
22. A pain disorder
23. A life-altering disease
24. A chronic or lifelong disease associated with a high level of disability
25. An unstable disease; from one hour/day/week or month to the next
26. A potentially progressive or fatal disease

Are there any tests which can be used to confirm a suspected M.E. diagnosis?

Yes. Whilst there is as yet no *single*, definitive laboratory test for M.E., there are a specific **series of tests** which enable a M.E. diagnosis to be confirmed. Virtually every M.E. patient will also have various abnormalities visible on physical exam.

As M.E. expert Dr Byron Hyde MD explains: 'The one essential characteristic of M.E. is acquired CNS dysfunction, [not] chronic fatigue. A patient with M.E. is a patient whose primary disease is CNS change, and this is measurable. We have excellent tools for measuring these physiological and neuropsychological CNS changes: SPECT, xenon SPECT, PET, and neuropsychological testing.' Thus it is these tests which are therefore most critical in the diagnosis of M.E., although various other types of tests are also useful. Some of the series of tests which can (in combination) help to confirm a M.E. diagnosis include:

* SPECT and xenon SPECT scans of the brain
* MRI and PET scans of the brain
* EEG brain maps and QEEG brain maps
* Neurological examination and the Romberg or tandem Romberg test
* Various tests of the immune system (eg. natural killer cells)
* Insulin levels and glucose tolerance tests
* Erythrocyte sedimentation rate (ESR)
* 24 hour Holter monitor
* Tilt table examination, exercise testing and chemical stress tests
* Physical exam

While various 'fatiguing conditions' with a variety of different aetiology's may be made up of vague and mild 'everyday' type symptoms, have no physical signs and no tests which can aid diagnosis, this is not the case with M.E. M.E. is a distinct neurological illness with a distinct list of symptoms, physical signs and diagnostic (and other) tests – it bears no relationship to such unrelated 'fatiguing conditions.' As M.E. authors Verillo and Gellman explain: 'Contrary to popular belief, ME is a distinct, recognisable entity that can be diagnosed relatively early in the course of he disease, providing the physician has some experience with the illness.' New clinical guidelines titled The Nightingale Definition of M.E. also make diagnosis easier than ever before; even for those with no experience with the illness. If all tests are normal, then a diagnosis of M.E. cannot be correct.

Further recommended reading:
Putting Myalgic Encephalomyelitis research and articles into context Because of the politics and financial interests involved in M.E. research it is vitally important that before you read anything about the illness that you read this paper first and first understand the context in which it was written.

For more information about the series of tests which may aid diagnosis see:

- Testing for M.E. by Jodi Bassett
- The Nightingale Definition of M.E. and The Complexities of Diagnosis by Byron Hyde MD
- 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 by Byron Hyde MD

The following texts provide overviews of what is known medically about M.E.:

- Myalgic Encephalomyelitis: The Medical Facts by Jodi Bassett
- M.E. vs MS: Similarities and differences by Jodi Bassett
- Putting research and articles into context by Jodi Bassett
- The effects of CBT and GET on patients with Myalgic Encephalomyelitis by Jodi Bassett
- The Nightingale Definition of M.E. and The Complexities of Diagnosis by Byron Hyde MD plus 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 by Dr Byron Hyde MD
- What is ME? What is CFS? Information for Clinicians & Lawyers by Eileen Marshall, Margaret Williams & Professor Malcolm Hooper, 2001
- Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research by Professor Malcolm Hooper
- Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC SCIENCE! and The Late Effects Of M.E. and A Rose by Any Other Name and Redefinitions of ME - a 20th Century Phenomenon by Dr Elizabeth Dowsett

- Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome by Malcolm Hooper Eileen Marshall Margaret Williams 174 pages.

- An Expert Summary of the Research From the Special Edition - Myalgic Encephalomyelitis: Clinical Working Case Definition. Journal of Chronic Fatigue Syndrome 2003 vol.11(1) p.68

Hundreds of individual research abstracts and articles by some of the world's leading M.E. experts are also available to view on this site.

The following sections are particularly relevant with regard to GET:

- Cardiac and Cardiovascular Research,
- Exercise Research,
- Mitochondrial Muscle Research and General Muscle Research

Samples of some of the relevant research in these sections are reproduced below.

Hundreds of individual research abstracts and articles by some of the world's leading M.E. experts and authors are also available to view; search for articles by topic or by author.

See: Myalgic Encephalomyelitis research and articles

This is a collection of literally HUNDREDS of some of the best M.E. research and articles, from some of the worlds leading researchers, doctors and M.E. advocates. Sections include: M.E. outbreaks, M.E. and children, viral research, cardiac research, the severity of M.E. and many more.

Essential reading on M.E.:

The book: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Edited by Byron Hyde, M.D. is also vital reading for anyone with a real interest in M.E.

This book provides, in one superb 75-chapter source, an up-to-date, comprehensive account of current knowledge concerning the history, epidemiology, children with M.E., investigation, virology, immunology, muscle pathology, host response, food intolerance, brain mapping, neurophysiology, neuropsychology, psychiatry, sleep dysfunction and much more. This is an essential reference book for medical, government and public library reference rooms. This text is a unique vehicle for researchers, physicians and other health education and government officials, and is also easily understandable by the general public. See the Review of this book for more information and for purchasing details.

Also highly recommended is: CFS: A Treatment Guide by Verillo and Gellman. See the Book Reviews section for more information about both of these (and many other) M.E. books.

References:

- Bassett, Jodi 2009, *What is Myalgic Encephalomyelitis?* [Online] Available: www.hfme.org/whatisme.htm

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.

5: patient accounts of CBT

Name: Andrew Porter **Country:** UK [Online]

The use of CBT, also known as Reverse Therapy in the UK, was to increase my level of physical exercise, and reduce the amount of sleep I had. Sadly, this caused all my symptoms to intensify, hence I became depressed through feeling so ill. Consequently, I had to be treated for depression after giving up the CBT protocol.

The use of CBT in the UK is dominant in dealing with M.E. as psychiatric medicine dominates, just as happened with Multiple Sclerosis and even Asthma. Sadly, psychiatry dominates in the UK, especially as it makes it a lot cheaper for the National Health Service to remove patients from what would otherwise be difficult and expensive investigations and treatments.

Name: Mark* **Country:** UK

I became ill in February 1993, just a few days after receiving a tetanus booster. The original diagnosis (no one noticed the tetanus booster at the time, or if they did, they didn't mention it - and no one's mentioned it since) was "acute stress". To this was later added "anxiety" and "depression".

My GP recommended I take longer and longer walks every day. This I did - until I literally dropped. After a very worrying struggle to get home again I realised this was not such a good idea. I kept trying to exercise, however, and it made me worse and worse, till it got to the point where I had no choice in the matter any more: I was bedridden most of the time. When I *was* able to go out, I couldn't do so without using a walking stick.

I also received a series of counselling sessions. The relaxation and visualisation exercises were fine, but the attempts at juggling disorientated and exhausted me. I never did learn.

In 1995 I was persuaded that I should stop using my walking stick and "think positively" and not "buy into" my condition. I struggled for about two months, but eventually had to go back to using the stick, as not only was my balance dangerously bad, but also the sheer physical strain of trying to walk unaided was making me worse generally.

That year I also followed a course of CBT. It did help me come to terms with the fact that I might never be well enough to work again (not a joyous realisation at the age of 40) and helped me cope with my handicaps, but I also eventually noticed that I was overdoing things physically - because I was trying to ignore my limitations, of course. To me, that is the worst danger of CBT when it comes to illnesses like M.E.

A couple of years later I managed to get a prescription from my GP which allowed me to have a discount when paying for a block booking of sessions at the local Fitness Centre. The first stage of the regime was using a treadmill and exercise bike. Total disaster. I had to give up, it was making me so bad. (I lost my money, including what I paid for the compulsory trainers, which were no use to me otherwise!)

The routines I have been taught over the years by physiotherapists (who were cognisant with the effects of M.E.) have been useful - but these involve very gentle exercises and stretching - nothing like Graded Exercise.

I know from hard experience how damaging pushing oneself both mentally and physically can be. I still overdo things, because, when I'm "well" enough, I keep trying. I still hope that eventually it will help, but after 12 years, common sense tells me that this is wishful thinking.

Name: Simon*

I had 6 sessions of CBT, at the time I was severely affected by ME/CFS had difficulty walking and standing for any length of time. My local support group (Susssex ME/CFS Society) heavily promoted CBT as the answer to all our problems. I had to pay privately to see a psychologist £45 per hr and had to travel 25 miles each way. The journey was the worst part.

On the first visit the psychologist claimed he could put me right in about 6 sessions - he gave me false hope. By the end of the third session I was no better and was starting to the notice that the same ground was being covered in each session, we were going round in circles and getting nowhere.

By the final session we had both come to the conclusion that CBT wasn't going to make any difference, my psychologist decided it wasn't what I needed after all - shame it took nearly £300 to reach that conclusion. Interesting nearly every Dr I have seen since being ill isn't a great believer in CBT for CFS - so I don't really understand why it is pushed so much.

Name: Clytie **Country:** Australia

CBT can be of enormous help to anyone suffering a long-term and profoundly disabling illness like ME/CFS. However, it's important to understand up front what it can't do. It can't change the physical realities in any way. The illness remains the same.

Name: Rose

My psychologist expected me to concentrate on talking to her for an hour after a long car journey. (I need to lie down for most of the day.) She clearly had no knowledge of M.E. (C.F.S.), & set me totally unrealistic tasks, then became cross because I hadn't done them. She told me that the pain didn't matter, it wouldn't harm me to complete her set tasks. It struck me that the money she was being paid (by the British national health) could have been much better spent on something helpful.

Name: Julia **Country:** UK

I had 10 (I think) sessions of CBT at Barts hospital a couple of years ago and am responding to your request for experiences of this. I had had ME nearly 15 years when I started the CBT, and felt strong enough mentally in myself to deal with any 'brain-washing' type stuff that might have come my way, and in fact there wasn't really any of that. I took up the offer of CBT partly to see what all the controversy was about and I have to say I did not find it a bad experience, but rather irrelevant.

My CBT counsellor was a pleasant woman, and we spent quite a lot of the time talking about the very recent ending of my long-term relationship. Although I ended the relationship and so was not completely devastated, there were issues to clear up, and as my ex-partner was black and so was my counsellor, I found her perspective interesting. She did do some sort of psychological tests on me, but pronounced me 'normal' and then seemed not really to know quite what to do with me.

I can't say I got nothing out of the sessions, but what I got was very minimal and certainly did not improve my ME - which anyway I didn't expect it would. Oftentimes any sense of support from the sessions was cancelled out by the exertion required to get to the hospital, of course! However, there was a small positive spin-off I think in that I was able to educate the counsellor about ME, recommending 'Stricken' and 'Shattered' for her to read. She was open-minded enough to respond positively, but unfortunately was only on a temporary contract, so if her perspective was changed by the reading it probably wont do PWME much good.

6: Patient accounts of GET

Name: Ruth **Country:** Ireland

I have been severely affected by M.E. for the past 14 years, completely bed bound for about 10 of those years, and had between 5% and 10% of my former health for the other 4. When I read headlines saying that an exercise regime was the answer to my ill health I couldn't understand it, as every time I tried to push myself physically even in small incremental steps I would deteriorate significantly. The last time I was able to walk I managed to convince myself that I was heading for a full recovery, and so increased my activity regardless of whether I was able for it, the result of this is that I have been unable to get out of bed for the past 6 1/2 years.

Graded Exercise is the worst possible thing for M.E. This is not to say that anybody with M.E. should not exercise, common sense tell us that it is preferable to be as active as possible, but in my experience it is critical to stay within your limits, whether that is a 20 minute walk or in my case a tightening and relaxing of my muscles 2 or 3 times a day. Having learned the hard way in future I will be allowing my body to dictate the amount of exercise I do even though that is one of the most frustrating things about this illness.

Regarding how exercise has come to be recommended by some medics, all I can assume is that they have not read the research behind the headlines, as even a cursory glance at the methodology reveals a sloppy scientifically lame approach biased towards a psychiatric model. This is wholly inappropriate for many reasons not least because M.E is classified as a neurological disease and upon closer inspection a proportion of these researchers may benefit financially from M.E being "treated" with graded exercise.

Name: Naomi

Its about time people knew how bad graded exercise is. i was pushed into it by my doctor, against my better judgement. it is recomended by quite a few doctors and 'specialists' so lots of people are trying it and end up more ill.

Name: Annette

I have done 2 GE programs under supervision, both were failures. They both left me far worse off than before for a long period. The first program was at a gym and involved low-impact exercises and then second was a walking program. The symptoms got much worse (sore throat, swollen glands, sinus infections, weakness, fainting) grew progressively worse and I had to abandon the exercise. The first one was early on in my illness (ME as per Ramsay) and probably led to the illness becoming permanent.

Name: Matthew* **Country:** UK

Exercise - handle with extreme care- ruined my life.

Before becoming ill, I was extremely sporty. Initially, after not being able to rest when having a virus on a school trip at an adventure centre and made do all the activities and never recovering, I was only very mildly affected. This I put down to giving up sport because of the muscle problems I developed so for the early years, I was able to go to school and then college full-time although I had to make cut-backs in most other areas of my life and, as my brain didn't work as well, struggled.

Anyway, my condition suddenly got much worse in the middle of my second year exams (a few hours after a tough 3-hour maths exam where I pushed myself hard to do questions (got a first, by the way), my throat swelled up and I felt feverish). Kept trying to exercise during the summer but developed more and more muscle problems - the physios said they never saw anything like it and x-rays of my back showed inflammation along my spine. I

took a year out of college as felt I wouldn't have been able for my finals with the health problems I had and set about trying to get back to normal health by gradually trying to build up the exercise.

Instead of improving, I kept getting worse and worse until I virtually collapsed and have been chronically and severely affected ever since and need a wheelchair to go distances more than 50 metres.

As nobody went to bed when they were sick in my house, neither did I so my symptoms in the early years could not have been put down to deconditioning.

I get so annoyed reading all the rubbish that is written about exercise and M.E./Chronic Fatigue Syndrome. Drugs which make a significant percentage of people worse are usually banned or have big warnings yet exercise ruins the lives of lots of people with ME/Chronic Fatigue Syndrome, like it has done mine, yet most medical people often aren't told by the people advocating the approach how dangerous it can be for patients. It really is unbelievable.

As I am so ill, even too much activity in my life (which is lived in the ground floor of my parents' house) can cause my glands to swell and my throat to get sore and generally feel malaised so I simply can't do this treatment now. I went to all this trouble to warn others - patients shouldn't have to wait until they are harmed by a treatment to learn it is a potentially dangerous treatment - they should be able to learn from other patients. If I had come across this information years ago, I might now be living a more normal life, rather than the life of a very disabled person.

Name: Joe*

GET: More harmful than beneficial for me.

I'm not sure I've ever been able to achieve graded aerobic exercise according to the standards set by some of the clinical studies. I haven't been as systematic at adding to the exercise in small increments over a period of weeks. But in a more limited way - perhaps 3-4 days of incremental increases - I typically found that my body was rebelling at the idea of doing the exercising. I found that it might be ok two days in a row, but more than that and it usually put me over my body's limit and I have a mild setback.
Actually I'd have to rank regular exercise as one of the most damaging treatments I've ever tried. As a stressor to my system it ranks up there with the other no-no's like not sleeping well for 3 or more nights; having an emotionally stressful event; getting chilled; and being exposed to some toxic chemical / substance.

Name: Jean*

GET: Harmful!!!! In my early years of CFIDS, I was under the mistaken impression that exercise might be helpful, and thus I pushed myself with disastrous results. Please do not exercise! Later, I found that I had tests that matched my profile to that of Dr. Martin Lerner's CFIDS patients with cardiomyopathy (viral heart infection). Cheney's theory that CFIDS can cause mitochondrial damage also asserts that exercise is downright dangerous. Be very, very wary.

Name: Ina

Having had this DD for 30 years, nothing set me back so far as graded exercise. I have still not regained the little strength I had prior to this exercise and it has been several years.

7: Summary of key points

This database may be summarised by the following key points:

1. 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.

2. The studies which support these theories and the use of these therapies have been conducted not on people with M.E. but instead on patients with an entirely unrelated health problem – the symptom of fatigue. The symptom of chronic fatigue and the distinct neurological illness M.E. each have a very different; cause, symptoms, aetiology, pathology (tests results), response to treatment, long and short term prognosis – and World Health Organization classification. People with the symptom of chronic fatigue (who merely qualify for a (mis)diagnosis of 'CFS') and those with M.E. do not represent the same patient group and cannot be studied interchangeably.

3. 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 unrelated patient groups so that they can fraudulently be discussed – to those who are not aware of the subterfuge involved – as if they were one and the same.

4. Although the new name and accompanying definition were created in response to an outbreak of what was unmistakably M.E., 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.' There are now more than 9 different CFS definitions, none of which selects for patients with M.E. In the two most commonly used definitions the only essential symptom required for the diagnosis of CFS to be made is 'chronic fatigue.' Both of these definitions are also designed to expressly *include* those with psychological or psychiatric 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. The overwhelming majority of the research and articles available today which use the term CFS are not in any way concerned with, or relevant to, Myalgic Encephalomyelitis patients. (That minuscule percentage which has sopme relevance to M.E. is also virtually always severely contaminated with 'CFS' propaganda and so of doubtful credibility.)

5. Why did M.E. suddenly need to be renamed or redefined? M.E. was 'redefined' not for medical reasons but for the benefit of a number of political and financial considerations. These are the reasons why the charade that M.E. could be a psychiatric disorder exists; not because there is good scientific evidence – or *any* evidence – for the theory, or because the evidence proving organic causes and effects is lacking; but purely because such a view is so **financially and politically convenient and profitable** on such a large scale to a number of extremely powerful corporations and Government departments.

6. Wessely, and many other key members of the Wessely school (who claim that M.E. is a psychological problem of fatigue) have been shown to have a number of vested interests with regard to M.E. (including long-held ties with insurance, chemical and pharmaceutical companies). Despite this, and the fact the work produced by this group (and their counterparts worldwide) 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, they have also driven governmental policy on M.E. in the UK (and worldwide) to an overwhelming extent. Wessely, Sharpe, Cleare and White (etc.) in the UK, their counterparts (and sometime collaborators) in the US; Reeves and Straus (etc. of the CDC), in Australia Lloyd and 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 CBT and GET as the most useful interventions for these patients. It is important to be aware that none of these groups is studying patients with M.E.

7. 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. 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 (and in some cases, death). For most M.E. patients CBT is useless and for a significant percentage it is harmful. CBT and GET are at best useless and at worst extremely harmful for M.E. patients. These treatments are also not always offered to M.E. patients 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.). In addition, many M.E. patients are ONLY offered 'treatments' such as CBT and GET – while access to even basic appropriate medical care is withheld.

8. There is no legitimate scientific debate about whether or not M.E. is a 'real' illness or not, or whether or not it is 'behavioural.' Substantial evidence exists to show that it is simply not possible that somatisation, secondary gain, malingering, aberrent illness beliefs – 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.' Strong evidence of the biological basis for the illness has existed since the 1950's and more than 1000 good articles now support the basic premises of M.E. as a debilitating lifelong organic neurological illness (which affects virtually all bodily systems) and which can occur in epidemic and sporadic forms.

9. The 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 major symptom to be misdiagnosed as having 'CFS.' 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. For example, those doctors which recommend CBT or GET to their patients 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.

   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.

10. **The disease category 'CFS' must be abandoned completely**
    - Patients with fatigue (and other symptoms) caused by a variety of different illnesses need to be diagnosed correctly with these illnesses if they are to have any chance of recovery; not given a meaningless Oxford or Fukuda 'CFS' misdiagnosis. 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.
    - The name Myalgic Encephalomyelitis must be fully restored and the WHO classification of M.E. (as an organic neurological illness at G93.3) must be accepted and adhered to in all official documentations and government policy.
    - People with M.E. must immediately stop being treated as if they are mentally ill, or mixed in with various 'fatigue' sufferers in any way. All forms of GET, and the abusive form of CBT, must be banned for all M.E. patients. It is illogical and unethical 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).

Again, there is no denying that the facts about Myalgic Encephalomyelitis may well be quite inconvenient to any number of doctors, politicians, media, and members of the public who have been operating under false pretences for so long with regards to this illness, with everything that that entails. But inconvenient facts or not, it is facts that they remain.

Additional note: There is no doubt that these theories and therapies are inappropriate for, and do not apply to, M.E. patients. However, considering that *(1) The government funded research produced by these groups 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, and greatly exaggerates the level of benefit derived from CBT and GET on the fatigue patients they study. (2)This coterie of psychiatrists (and others) has a number of conflicts of interest and proven long-held affiliations with corporate industry* – clinicians should also be very wary about accepting that the claims made by these groups are legitimate and based on objective analysis of the evidence with regard to true 'chronic fatigue' sufferers either.

The evidence supporting the beneficial effects of CBT and GET in these patients is as best flimsy, as many of the compelling articles and evidence provided in Section 3 of this guide made very clear. Treatment and aetiology for every illness (or symptom) must be determined solely by legitimate science conducted by groups which do not have a direct conflict of interest in any particular outcome.

This guide is available online at: www.hfme.org/cbtandget.htm

For abstracts and links to hundreds more research studies and articles on all aspects of M.E. see: www.hfme.org