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

This 170 + 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, and themselves, as well as society in general.

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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.

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

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

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

**Chronic fatigue** is a symptom of many different illnesses and has a large number of different and unrelated causes. People with chronic fatigue may be fatigued because of vitamin deficiency, sleep disorder, depression, cancer, burn-out, Multiple Sclerosis, and a large number of other psychiatric and miscellaneous non-psychiatric illnesses.

This symptom may persist for weeks, months or years and the severity level can vary from very mild to severe. 20% of the population or more may suffer from some form of chronic fatigue.

Myalgic Encephalomyelitis is not merely a symptom, but instead a distinct *disease*. It has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disease with the code G93.3. Myalgic Encephalomyelitis is a systemic acutely acquired illness initiated by a virus infection which is characterised by damage to the brain stem (a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions) which results in dysfunctions and damage to many of the body’s vital systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. is primarily neurological, but symptoms may also be manifested by cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. More than 64 distinct symptoms have been authentically documented in M.E., several of which are unique to the disease. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely ‘fatigued’ instead of having M.E.

M.E. can occur in both epidemic and sporadic forms and over 60 outbreaks of the illness have been recorded worldwide since 1934. M.E. can be extremely disabling and in some cases the illness is fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis 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 therapies 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]).

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‘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 alloying 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 not just for sufferers of M.E. but for their families as well.

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 Wesselly (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.

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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: www.hfme.org

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 basis 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. Kandoff 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 or 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:  

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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).


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

It is vital that M.E. patients avoid physical over-exertion and are never encouraged to be active beyond their individual limits particularly in the early and acute stages of the illness, but also at any stage of the illness as this can greatly damage a patient’s chances for future improvement or recovery. Graded exercise cannot improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E. (Ramsay 1986, [Online]) (Hyde 2003, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 – 43) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999, [Online]) (Dowsett n.d.b, [Online]).

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

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

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

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

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

One of the main M.E. misconceptions is that while walking a few steps must of course require additional bodily resources and additional cardiac output, time spent thinking, looking, listening or experiencing other sensory stimuli does not. But this is not the case. Not only physical effort, but also cognitive effort, requires additional resources which an M.E. patient may not have. The brain contains some 100 billion neurons connected to some 10,000 relay stations and this enormous electrical activity creates a massive need for energy and other bodily resources. The brain uses up to 25% of the entire body's demand for glucose, 25% of the blood pumped from the heart goes to the brain and the brain also needs 25% of the body's oxygen supply. (Blood supplies nutrients like glucose, protein, trace elements, and oxygen to the brain.) So of course, every extra second of 'electrical activity' - every thought, every feeling, every noise heard or sight seen - requires additional cardiac output, makes additional oxygen and glucose demands, and so on, in just the same way as does a physical activity such as walking; if not more so. So in addition to physical activity, the list of things that can cause similar severe relapse in M.E. patients also includes cognitive exertion, sensory input and orthostatic stress. Anything that makes the body work harder or have to adjust in some way, in effect (Dowsett n.d.d, [Online]).
Thus any type of CBT will cause severe relapse in those who are severely affected in this way thus CBT can NOT be considered safe for all M.E. sufferers (Carruthers et al. 2003, [Online]).

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

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

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

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

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

- These brief comments on the effects of CBT and GET are taken from the more detailed and comprehensive paper: The effects of CBT and GET on patients with Myalgic Encephalomyelitis, please see this paper for more information.
- For more information about forced exercise and other ‘treatments’ used on M.E. children see: What is Myalgic Encephalomyelitis? Extra extended version

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

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

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

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

It is also of great concern that many M.E. patients are ONLY offered ‘treatments’ such as CBT and GET – while access to even basic appropriate medical care is withheld. Of the 25% of patients who are severely affected by the illness (and are bed-bound and housebound) around half have no contact with the health service at all as they are
seldom able to obtain housecalls, for example. (Dunn 2005, [Online]). Thus a significant percentage of very physically ill and vulnerable M.E. patients are simply left to suffer and die at home without any medical care or support. (Hooper 2003, [Online])

- For more information on this see: Comments from Greg Crowhurst of the 25% M.E. Group to the Gibson Enquiry. Many more articles on this topic are also available in Section 3, Section 5 and Section 6 of this guide.
- A recent example of a M.E. sufferer being taken into psychiatric care against their will is the case of Sophia Mirza in the UK. Tragically Sophia died of her illness not long after this ‘treatment.’ For information on this tragic case see: What is Myalgic Encephalomyelitis? Extra extended version.

Conclusion

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

Substantial evidence exists to show that it is simply not possible that somatisation, secondary gain, malingering, aberrant illness beliefs, too much focus on normal bodily sensations, irrational fear of exercise leading to deconditioning, being rich and white, being poor and from an ethnic minority, being lazy and unwilling to work, being too highly driven and perfectionistic and working too hard, faulty thought processes, lack of motivation, long-term stress, acute stress, abuse in childhood, a genetic inability to deal with normal levels of stress, inadequate coping strategies and contagious sociological hysteria – or any or the other ridiculous and often contradictory ‘theories’ put forward by these vested interest groups – play a role in causing or perpetuating authentic M.E.

The psychological or behavioural theories of M.E. are no more scientifically viable than are the theories of a ‘flat earth.’ They are pure fiction. Strong evidence of the biological basis for the illness has existed since the 1930s and 1950s and more than 1000 good articles now support the basic premises of M.E. as a debilitating organic neurological illness. Thus this is not simply theory, but is based upon an enormous body of clinical information. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999, [Online]) (Dowsett n.d.b, [Online]). M.E. is not ‘medically unexplained’ (or ‘unexplainable’) and many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research articles. These are well-documented, scientifically sound explanations for why patients are often bedridden and unable to maintain an upright posture.

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

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

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

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

‘CFS’ is merely a scam invented by insurance companies motivated by profit without regard for truth or ethics. These groups are acting without any regard for the (extreme) suffering and the additional avoidable deaths they are causing. These groups are acting criminally. This scam is tissue thin and very easily discovered if one merely takes a small amount of time to look at all of the evidence.

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

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

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

So where do we go from here?
Sub-grouping different types of ‘CFS’ or renaming would achieve nothing and only create yet more confusion – which the corporations involved would no doubt continue to take advantage of, to the continued detriment of patients. The only way forward is that:

1. The artificial disease category ‘CFS’ must be abandoned. There is no such disease/s as ‘CFS’ – the name ‘CFS’ and the bogus disease category of ‘CFS’ must be abandoned (along with the use of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ ‘CFIDS’ and 'Myalgic Encephalopathy' and others).

Patients with fatigue (and other symptoms) caused by a variety of different illnesses need to be diagnosed correctly with these illnesses if they are to have any chance of recovery; not given a meaningless Oxford or Fukuda ‘CFS’ misdiagnosis. (Some of the conditions commonly misdiagnosed as ‘CFS’ are very well defined and well-known illnesses and very treatable – but ONLY once they have been correctly diagnosed). Patients with M.E. need this same opportunity. Each of the patient groups involved must be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group.

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

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

The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. The 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’ suffersers 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 PHILOSOHY 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.

- **References**

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

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

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

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

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

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

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

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

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

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

Professor Malcolm Hooper explains that ‘Wessely school’ psychiatrists, and those who follow them, have: ‘Built their careers and reputations on denying the physical nature of M.E., with the result that untold numbers of chronically and seriously ill patients are bullied, derided, threatened and driven to suicide by being told that they are not physically ill but are suffering from “aberrant illness beliefs”’. WesselySchool psychiatrists have been described in the eBMJ (N Portman, 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

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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.
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.
The effects of CBT and GET on patients with M.E.
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Taken from www.hfme.org

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 involving miscellaneous psychiatric and non-psychiatric ‘fatigue’ patients which qualify for a diagnosis of ‘CFS,’ and their response to these treatments, have no more relevance to M.E. sufferers than they do to diabetes patients, cancer 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:

1. What is the effect of graded exercise therapy (GET) on Myalgic Encephalomyelitis (M.E.) patients?
2. What is the effect of cognitive behavioural therapy (CBT) on Myalgic Encephalomyelitis (M.E.) patients?

1. 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 beyond their individual post-illness limits. 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’ as the defining or primary feature. 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 is quite distinct from the ‘chronic fatigue’ seen in many other illnesses.

Fatigue and feeling ‘tired all the time’ are not at all the same thing as the very specific type of paralytic muscle weakness or muscle fatigue which is characteristic of M.E. (and is caused by mitochondrial dysfunction) and which affects every organ and cell in the body; including the brain and the heart. This causes – or significantly contributes to – such problems in M.E. as; cardiac insufficiency (a type of heart failure), orthostatic intolerance (inability to maintain an upright posture), blackouts, reduced circulating blood volume (and pooling of the blood in the extremities), seizures (and other neurological phenomena), memory loss, problems chewing/swallowing, episodes of partial or total paralysis, muscle spasms/twitching, extreme pain, problems with digestion, Raynaud’s phenomenon, vision disturbances, breathing difficulties, and so on. These problems are exacerbated by even trivial levels of physical and cognitive activity, sensory input and orthostatic stress beyond a patient’s individual post-illness limits leaving M.E. patients extremely disabled (Bassett 2009, [Online]).

People with M.E. are experiencing a form of heart failure which can be exacerbated by even relatively low levels of activity. Many patients are housebound and bedbound and often are so ill that they feel they are about to die. Some M.E. patients do die due to overexertion. People with M.E. would give anything to instead only be severely ‘fatigued’ or tired all the time.

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

The paralytic muscle weakness seen in M.E. affects all muscles including the heart and causes what is commonly known as exercise intolerance; that patients relapse with excessive physical and cognitive exertion, as well as with orthostatic stress. These features are a core part of what M.E. is as they are responsible for causing much of the symptomatology and disability associated with the disease (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d., [Online]).
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; physical, cognitive or orthostatic overexertion 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 years 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.’

Also from Dr Elizabeth Dowsett:

The brain has often been likened to a computer. However, there are fundamental differences in its essential function of processing, comparing and storing information. Unlike a computer, which can be switched on and off and is programmed to give set answers to a single question, the chemical transmitter bridging the synapse introduces a variability into the on-going message and “Neuronal Plasticity” into the receiving/transmitting network. It has been shown that similar modifications in response may be induced by virus infection. 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, using up 20% of the entire body’s demand for oxygen and glucose. Recent studies of the brain stem by SPECT scan, indicate hypoperfusion and low metabolic activity in subjects with M.E.

Modern research indicates disturbed metabolism in many areas essential to motor control in the brain stem of patients with M.E., the majority of whom have evidence of inco-ordinated muscle twitching after slight exertion.

A good memory demands normal functioning of almost all areas of the cerebral cortex, the basal nerve centres of the mid brain (eg the thalamus and hippocampus) and their interconnecting pathways through the brain stem. Fluctuations of metabolic activity in these areas (often made worse by physical and mental [overexertion]) have been reported in SPECT scans of patients with M.E., the vast majority of whom complain of difficulty with short-term memory (n.d.c, [Online]).

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]). Dr. Elizabeth Dowsett also explains that:

Scientific discoveries recently reported, indicate that embryonic stem cells left over from foetal development, remain in the brain tissue during adult life and are capable of “running repairs” (thus patients are able to recover after head injury, stroke and relapse in ME). However, overuse of these repairs, as in ME (when the patients are overstressed [overexerted] physically or mentally) will cause unnecessary deterioration which may then become irreparable. Intervention in the form of financial, rehabilitation and nutritional support can do much to prevent the physical, occupational and other deterioration in the quality of life for a large group of patients now between 40 and 60 years of age, to say nothing of educational loss in children.

HEALTH SERVICE INTERVENTIONS: It is sad to read that these are said to be of dubious priority in the present state of the NHS when it is known that the correct type of rehabilitation can stabilise the illness. This requires access to local facilities
without discrimination against patients with a diagnosis of ME, together with a domiciliary nursing service for the bed-bound who are unable to travel (2002b, [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 basis 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 chronic host infection
- major or no cardiac disease depending on the virulence of the subtype
- 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
- cardiac disease depending upon the immunological variability of the host (Hyde & Jain 1992a, p. 40).

An enterovirus would also explain the; age variation, sex variation, obvious resistance of some family members to the infection and the effect of physical activity (particularly in the early stages of the illness) in creating more long-term/severe M.E. illness in the host (Hyde & Jain 1992a, p. 40). There is also the evidence that; M.E. epidemics very often followed polio epidemics, M.E. resembles polio at onset, serological studies have shown that communities affected by an outbreak of M.E. were effectively blocked (or immune) from the effects of a subsequent polio outbreak, evidence of enteroviral infection has been found in the brain tissue of M.E. patients at autopsy, and so on (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 also 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:

The subject of vascular pathology is not new. The fact of the children dying of a Parkinsonian-like vascular injury to the basal ganglia in Iceland during the Akureyri M.E. Epidemic is an obvious indication of the CNS vascular effects in M.E. Vasculitis has been well documented by Dr. E. Ryll in his description of the epidemic in the San Juan Mercy, Sacramento California Hospital in 1975. He described this M.E. epidemic as an epidemic vasculitis. He was correct. Following my 21 years of examining M.E. patients and 16 years of subjecting M.E. patients to brain imaging techniques, it has become obvious to me that we are dealing with both a vasculitis and a change in vascular physiology. Numerous other physicians have supported this finding.

The recent interpretation of the cause of Multiple Sclerosis (MS), as an injury of the microvasculature causing the injury of the schwann cells that in turn causes the demyelination injuries of MS has been added to that of paralytic
poliomyelitis as an essential vascular injury. Paralytic poliomyelitis was thought to be a primary injury to the anterior horn cells of the spinal cord but is now recognized as a vasculitis injuring the circulation to the anterior horn cells. Poliomyelitis is generally a non-progressive, specific site injury, although post-polio syndrome with demonstration of subcortical brain changes has challenged that belief. MS is a recurrent more fulminant physiological vascular injury. M.E. appears to be in this same family of diseases as paralytic polio and MS. M.E. is definitely 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 (2007, [Online]).

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 true 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]).

We also have ample evidence from other doctors who have a significant involvement with M.E. patients (although for various reasons they cannot be considered M.E. experts, as such), indicating that M.E. patients have an abnormal and negative response to exertion. This includes the following:

1. 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 M.E.* pumped less blood than it did at rest. Peckerman is on record as saying that it is a ‘progressive disease’ and that, ‘Basically we are talking about heart failure. A drop in [blood pumped by the heart] during exercise is not a typical response.’

This important research showed that, without exception, every disabled M.E. patient is in heart failure. The New Jersey team found evidence of the “Q” problem in M.E. ‘Q’ stands for cardiac output in litres per minute. In M.E. patients, Q values correlated, with great precision, with the level of disability. Q was measured using impedance cardiography, a clinically validated and Government agency-recognised algorithm. (Impedance cardiography is not experimental.)

Normal people pump 7 litres of blood per minute through their heart, with very little variance, and when they stand up, that output drops to 5 litres per minute (a full 30% drop, but this is normal). Those two litres are rapidly pooled in the lower extremities and capacitance vessels. Normal people do not sense the 30% drop in cardiac output when they stand up because their blood pressure either stays normal or rises when they stand up, the body will defend blood pressure beyond anything else in order to keep the pulse going.

What the New Jersey team found in people with M.E. was astonishing – when these disabled patients stand up, they are on the edge of organ failure due to extremely low cardiac output as their Q drops to 3.7 litres per minute (a 50% drop from the normal of 7 litres per minute).

The disability level was exactly proportional to the severity of their Q defect, without exception and with scientific precision. In this Peckerman study, the data on the disabled M.E. patients reveals that even when they

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are lying down, their Q is only 5 litres per minute. The lower the Q, the more time the patient will spend lying down because lying down is the only time they come close to having sufficient cardiac output to survive (Peckerman et al. 2003, [Online]) (Hooper et al. 2007, [Online]) (Web M.D. 2009, [Online]).

2. Dr Cheney (following on from the Peckerman study) explained recently that because it takes more metabolic energy for the heart to relax and fill with blood than it does for it to squeeze and pump blood, the hearts of people with M.E. don’t fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. and much of the disability of M.E. (The following summary of Cheney’s work (most of which was made public only in the form of recorded lectures) is taken from the Corporate Collusion paper by Professor Malcolm Hooper et al.)

Cheney comments that patients with M.E. suffer from cardiac problems since they cannot pump sufficient blood to the heart. He explains that the inability of very ill patients to stand up is the body protecting itself from cardiac stress and possible death. Cheney explains that if patients draw down their lifestyle to live within the means of the reduced cardiac output, then progression into congestive cardiac failure (CCF) is slowed down, but if things continue to progress, a point will be reached where there is no adequate cardiac output, and dyspnoea will develop, with ankle oedema and other signs of congestive cardiac failure. In order to stay relatively stable, it is essential for the patient not to create metabolic demand that the low cardiac output cannot match. Attempts to push beyond limits will cause injury or death.

Cheney also explains that M.E. patients have a high heart rate but a low cardiac output. In M.E. there is a cardiac dimension that is independent of (but not excluding) autonomic function or blood volume. A mismatch between metabolic demand and cardiac output, even very briefly, will kill. If the cardiac output goes down, in order not to die, there is a rise in noradrenergic tone (also involving the adrenal glands) to bring the output back up. This is a serious problem, because when the adrenals are exhausted, there will be low cardiac output. There is no such thing as an M.E. patient who is NOT hypothyroid: this has nothing to do with thyroid failure, but everything to do with matching metabolic demand and cardiac output.

Half of patients exhibit atrial cavitation, and when these patients stood up, the filling volume collapsed. M.E. patients “squeeze the hell” out of their left ventricle, resulting in a "whopping" 70% increase in left ventricular wall motion thickness. The reason why patients are squeezing so hard is because they do not have enough energy to fill the chambers of the heart properly so they are trying to compensate by squeezing a lot harder (ie. the way patients are compensating for this loss of cardiac output is by squeezing the left ventricle much harder). There are significant consequences of this. One consequence is that M.E. patients become asynchronised (ie. the heart can be filling and ejecting at the same time). If out of synchrony, the ventricle cannot cope, so cardiac output is severely degraded.

Cheney posits that when faced with a low Q, the body sacrifices tissue perfusion in order to maintain blood pressure: ie. microcirculation to the tissues of the body is sacrificed to maintain blood pressure so that the person does not die in the face of too low a cardiac output. This compensation is what is going on in the M.E. patient. Cheney states that it is important to note that the body does not sacrifice tissue perfusion equally across all organ systems: instead, it prioritises the order of sacrifice and one can observe the progression of M.E. in a patient by noting this prioritisation.

Two organ systems in particular have a protective mechanism (the Renin Angiotensin System, or RAS) against restricted tissue perfusion: the lung and the kidneys. These organs can sustain the greatest degree of Q problems because of this extra protection. Additionally, the heart and the brain also have this extra protection, even in the face of an extremely low Q. Therefore the lung, the brain, the kidneys and the heart are a bit more protected from a drop in Q than the liver, the gut, the muscles and the skin.

a. The first to be affected is the skin: if the microcirculation of the skin is compromised, several problems can arise. The body cannot thermoregulate anymore: the patient cannot stand heat or cold and if the core temperature rises, the patient will not be able to sleep and the immune system will be activated. In order to regulate that problem, the body will kick in thyroid regulation which will down-regulate in order to keep the body temperature from going too high. The patient then develops compensatory hypothyroidism, which means that now the patient will have trouble with feeling cold. Also, the body will not be able to eliminate VOCs (volatile organic compounds), which are shed in the skin’s oil ducts, so VOCs build up in the body’s fat stores and the patient becomes progressively chemically poisoned by whatever is present in the environment.

b. The second effect: the next microcirculation to be sacrificed is that to the muscles and the patient will have exercise intolerance. If things get still worse, the patient begins to experience pain in the muscles. If the microcirculation to the joints becomes compromised, the patient starts to have arthralgia linked to this circulatory defect.

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c. The next system to be compromised is the liver and gut. One of the first things the patient may notice in this stage of disease progression is that there are fewer and fewer foods that can be tolerated, partly because microcirculation is necessary for proper digestion. Also the body will not secrete digestive juices so whatever food is tolerated will not be digested: if food cannot be digested, there will be peptides that are only partially digested and therefore are highly immune-reactive; they will leak out of the gut into the bloodstream, resulting in food allergies or sensitivities. The body will be unable to detoxify the gut ecology, so the gut will begin to poison the patient, who will feel as if poisoned, with diarrhoea, constipation, flatulence and other gut problems.

d. The fourth affected system is the brain: Cheney posits that there is a devastating effect in the brain as a result of liver / gut dysfunction, which can quickly toxify the brain, resulting in disturbances of memory and of processing speed. Also, the hypothalamus begins to destabilise the patient from the autonomic nervous system perspective. In all probability, the brain and heart suffer simultaneous compromise, but patients usually notice the brain being affected much earlier than the heart – this is because heart muscle cells have the greatest mitochondrial content of any tissue in the body, so when the mitochondria are impaired, the heart muscle has the greatest reserve. Even if the patient is sedentary with not too much demand on the heart, they can still think and make great demands on the brain, and energy is energy, whether it is being used physically or cognitively.

The fifth affected system is the heart: Cheney posits that the effect of compromised microcirculation upon the heart has an “a” part and a “b” part: part “a” is the manifestation of microcirculation impairment and part “b” is “the event horizon”.

Part “a”: manifestation of microcirculation impairment: the initial manifestation of microcirculatory impairment of the heart is arrhythmia with exercise intolerance: when the patient goes upstairs, more cardiac output is needed but the patient cannot sustain it. When there are even more severe microcirculatory problems, the patient starts to get chest pain as the myocardial cells die because they cannot get adequate oxygen.

Part “b”: the event horizon: (once this line is passed, there is no going back): Cheney’s view is that when the microcirculation defect within the heart itself begins to impact Q, a vicious circle begins – microcirculation impairment reduces the Q, which produces more microcirculation impairment, which produces even more Q problems, so down goes the patient into the next phase of cardiac failure, which involves the lungs.

The sixth affected system is the lung and kidney: this leads to congestive heart failure and pulmonary oedema, then the kidney is affected (the kidney is the last to go because it has the RAS back-up system). Combined with liver impairment, this stage is known as hepatorenal failure. A patient will know if s/he eventually loses the ability to compensate if, when they lie down, they are short of breath. Cheney’s view is that cardiac muscle has lost power because the mitochondria are dysfunctional (ie. there is an energy-production problem in the cells).

The red blood cells of patients with M.E. have been found to be deformed. When deformed, they cannot get through the capillary bed, causing pain. An indication of such deformity is a drop in the sedimentation rate (SED, or ESR) and Cheney (along with Dr Hyde and other M.E. experts) has observed that when measured in a laboratory, M.E. patients’ sedimentation rate is the lowest he has ever recorded, which confirms that M.E. patients have an induced haemoglobinopathy. Cheney has stated that the M.E. patients with the lowest sedimentation rate may have the greatest degree of pain. The more deformed the red blood cells, the more pain may be experienced. Some M.E. patients have a problem similar to that of sickle cell anaemia in this regard, and sickle cell patients have unbelievable pain. Cheney emphasises that it is bad enough when patients do not perfuse their muscles and joints (because of poor microcirculation) but it is even worse when red blood cells are so deformed that they can barely get through the capillaries or are blocked entirely. Cheney notes that in the Laboratory Textbook of Medicine, there are only three diseases that lower the sedimentation rate to that level: one is sickle cell anaemia (a genetic haemoglobinopathy); the second is M.E. (an acquired haemoglobinopathy) and the third is idiopathic cardiomyopathy. (The latter being one way in which the cardiac problems of M.E. are described.)

Cheney observes that in order to improve cardiac output, patients need to lie down, as this increases the cardiac output by 2 litres per minute. He notes that some patients need to lie down all the time to augment their blood volume in order to survive (Cheney 2006, [video recording]) (Peckerman et al. 2003, [Online]) (Hooper et al. 2007, [Online]).

Findings which showed mitochondrial dysfunction similar to mitochondrial encephalomyopathy also led Dr Cheney to comment, ‘The most important thing about exercise is not to have [patients with ME] do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA’ (Williams 2004, [Online]).
Note that Dr Cheney cannot be said to be a M.E. expert, although he does deal primarily with M.E. patients and his comments on cardiac insufficiency can (and do) only relate to genuine M.E. patients as this finding is unique to M.E. patients. Unfortunately Cheney uses the terms ‘CFS’ and ‘CFIDS’ to refer to M.E. patients and, worse, unfortunately mixes in some medical and political facts about ‘CFS’ and ‘CFS’ patients (patients with diseases other than M.E.) into his 20 years of M.E. research. Thus not all of his work relates 100% to M.E. unfortunately. See: Is Cheney talking about M.E. or ‘CFS’? for more information.

Dr Peckerman, like Cheney, has been involved in the study of the abnormalities unique to M.E. Unfortunately however he has used the terminology and definitions of ‘CFS’ and has included a vast amount of ‘CFS’ propaganda in his work. Thus while Dr Peckerman has some legitimate knowledge of the M.E. disease process, he cannot be considered a M.E. expert. Note also that both of these doctors do not use anything like the most severely affected M.E. patients in their research.

As these comments clearly indicate, the adverse response to physical activity in M.E. patients is not ‘medically unexplained’ – research has found a number of sound medical reasons why M.E. sufferers are so physically disabled and limited, and unable to maintain an upright posture. These include; evidence of damage to the central nervous system (and autonomic and sympathetic nervous systems, causing a loss of normal internal homeostasis), damage to cardiac muscle and (many other cardiac and cardiovascular abnormalities including evidence of cardiac insufficiency), abnormalities and damage to muscle, immune system abnormalities, respiratory abnormalities and also a variety of abnormalities at a cellular level (eg. mitochondrial defects).

It is also worth noting that none of these abnormalities can be explained by so-called ‘deconditioning’ – the supposed reason for the recommendation of therapies such as GET.

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.

For more information on why exercise programs are so dangerous for M.E. patients see also the medical overviews given in: Profits Before Patients?, CRITICAL CONSIDERATIONS, Science or Psychology? and Corporate Collusion by Eileen Marshall and Margaret Williams and/or Professor Hooper.

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

- 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. This was the highest negative rating of any of the pharmacological, non-pharmacological and alternate approaches of management covered in the questionnaire. 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 (conducted by the 25% M.E. Group) again found that graded exercise was by far the single most harmful treatment of any of the pharmacological, non-pharmacological and alternate approaches of management covered in the questionnaire. 95% of those that had tried GET 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]).

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. Abnormalities found so far include the following:

<table>
<thead>
<tr>
<th>Response to Exercise</th>
<th>Healthy People</th>
<th>M.E. Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of well-being</td>
<td>Invigorating, anti-depressant effect</td>
<td>[Pain, exacerbation of many of all symptoms accompanied by overwhelming sensations of being intensely ill (see the description below)]</td>
</tr>
<tr>
<td>Resting heart rate</td>
<td>Normal</td>
<td>Elevated</td>
</tr>
<tr>
<td>Heart rate at maximum workload</td>
<td>Elevated</td>
<td>Reduced heart rate</td>
</tr>
<tr>
<td>Maximum oxygen uptake</td>
<td>Elevated</td>
<td>Only ½ that of sedentary controls</td>
</tr>
<tr>
<td>Age-predicted target heart rate</td>
<td>Can achieve it</td>
<td>Can NOT achieve it</td>
</tr>
<tr>
<td>Heart functioning</td>
<td>Increased</td>
<td>Sub-optimal level</td>
</tr>
<tr>
<td>Cerebral blood flow</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>Cerebral Oxygen</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>Body temperature</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td>Respiration</td>
<td>Increased</td>
<td>Breathing irregularities: shortness of breath, and irregular breathing</td>
</tr>
<tr>
<td>Cognitive processing</td>
<td>Normal, more alert</td>
<td>Impaired</td>
</tr>
<tr>
<td>Oxygen delivery to the muscles</td>
<td>Increased</td>
<td>Reduced</td>
</tr>
<tr>
<td>Gait Kinematics</td>
<td>Normal</td>
<td>Abnormalities</td>
</tr>
<tr>
<td>Recovery period</td>
<td>Short</td>
<td>[Days, weeks or months, or longer (or recovery may not occur and the relapse/damage may be semi-permanent or permanent. In a small percentage of cases, overexertion of the M.E. patient causes death)]</td>
</tr>
</tbody>
</table>

- This (modified) chart is taken from an article by M. van de Sande. See Testing for M.E. for more information about exercise testing in M.E.

If patients with M.E. exceed their individual physical, cognitive, orthostatic and other limits, they will experience some combination of the following:

- A mild-severe (acute or delayed) worsening of one or more symptoms for hours, days or longer afterward
- A mild-severe (acute or delayed) worsening of virtually every symptom for hours, days or longer afterward
- A severe (acute or delayed) worsening of the base level of illness/disability for hours/weeks/months or even years afterward, or
- A permanent worsening of the base level of illness/disability (i.e. permanent physical damage is caused and chances for significant recovery are adversely affected or lost entirely. Painstaking gains made slowly over many months or years may also be lost.)

It is also important to be aware that repeated or severe overexertion can also result in the death of the M.E. patient. (Death in M.E. is most often caused by heart failure or multiple organ failure.) (Bassett, 2009, [Online]).

The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) in M.E. include:

A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels post-M.E.

B. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.

C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardic, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.

D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient’s pre-illness tolerances and abilities.

E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.

F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.

G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.

H. The activity limits of M.E. are not short term: a gradual (or sudden) increase in activity levels beyond a patient’s individual limits can only cause relapse, disease progression or death in patients with M.E.

I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion; there is also a base level of illness which can be quite severe even at rest.

J. Repeated overexertion can harm the patient’s chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.

K. Not every M.E. sufferer has ‘safe’ activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected.
Can GET at least help some of those with mild M.E.?
It is sometimes claimed that while exercise programs are not safe or appropriate for the severely affected, that mild or moderately affected M.E. sufferers can benefit from such interventions. But this assertion is NOT supported by the evidence. Some ‘fatigue’ sufferers have been shown to benefit from GET, but the results of these studies are no more relevant to mild M.E. sufferers than they are to severe M.E. sufferers; people with ‘fatigue’ do NOT have mild M.E. any more than they have mild multiple sclerosis, or mild cancer or any other illness. They are an entirely unrelated patient group. Thus graded exercise programs may help some fatigue sufferers but this is irrelevant to those who have M.E. Again, it has been shown that graded exercise programs are the actual reason many with M.E. are so severely affected ie. they were not severely affected before they were given advice to exercise or enrolled in formal GET programs. Thus GET should not be considered safe or useful for M.E. sufferers of any severity (25% M.E. Group 2004, [Online]).

Research has also proven that how much physical and cognitive overexertion a person can tolerate without serious damage depends on the severity of their illness. For example, we know that moderately affected patients can die from exercise sessions. For example, there is the case of the UK MP Brynmor John who had M.E. and was advised to ‘exercise himself back to fitness’ and who as a result of complying with this advice collapsed and died coming out of the House of Commons gym. Then there is the case of Sophia Mirza, in the UK who died from M.E. after being forced into inappropriate and abusive psychiatric care. Sophia had severe M.E. and was of course not capable of any exercise. Nonetheless, she was inappropriately removed from her home and given inappropriate care. She was cruelly killed by being forced into what to most people would have been only very minor or trivial exertions.

For all of these reasons, it is vitally important that patients are allowed to judge for themselves how much activity it is safe and wise for them to attempt. Patients are the best judges of their own limits, and patients’ judgements must not be over-ruled. Patients should never be advised, encouraged or forced to be more active than their severely damaged bodies can handle; these decisions cannot safely or ethically be made by any third party.

It is vital that M.E. patients avoid physical over-exertion and are never encouraged to exercise (or be mentally active, or cause orthostatic stress) 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 patients 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. There is nothing to be gained by people with M.E. pushing themselves beyond their individual physical limits; this can only result in unnecessary and sometimes very severe and prolonged relapses, disease progression, or even death (Ramsay 1986, [Online]) (Hyde 2003, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, [Online]).

For more information on why exercise programs are so dangerous for M.E. patients see also the medical overview: Profits Before Patients?, CRITICAL CONSIDERATIONS, Science or Psychology? and Corporate Collusion by Eileen Marshall and Margaret Williams and/or Professor Hooper.

See Testing for M.E. for more information about the series of tests which can be used to confirm a suspected M.E. diagnosis. If you have M.E. see Treating Myalgic Encephalomyelitis - The basics and Treating Myalgic Encephalomyelitis - avoiding overexertion for more on the importance of avoiding over-exertion.

2. 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; 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:

3. 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. This type of CBT is also given to patients with cancer and a wide array of other chronic illnesses (Carruthers et al. 2003, [Online]).

4. 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.’ ie. ‘Patients are sick only because they believe they are sick.’ According to this theory of CBT, this therapy is potentially curative (Carruthers et al. 2003, [Online]).

Surveys of M.E. patients on the effects of cognitive behavioural therapy found:
The hypothesis behind the first type of CBT is reasonable. This type of CBT may 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. As with other chronic illnesses, the indications are that this type of CBT should be recommended or provided on a patient by patient basis only to those patients who have a specific need for such an intervention. CBT should not be considered essential for all – or even most – M.E. patients.

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 ie. they cannot travel out of the house, speak or listen to speech for more than a few seconds or minutes etc. either without severe relapse or at all. One of the main 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. [Online]). (See: Why patients with severe M.E. are housebound and bedbound for more information.)

Any type of CBT will cause severe relapse in those who are too severely affected to safely participate. This relapse may last many weeks or months, or even be life-long or result in death. CBT can NOT be considered safe for all M.E. sufferers.

The hypothesis behind the second type of CBT however, is far from reasonable. Despite the large body of research which compellingly and conclusively disproves this hypothesis, the assumption of its truth by some has led to this treatment being used on many M.E. sufferers particularly in the UK, The Netherlands and to a lesser extent, Australia. This unscientific and unethical 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 blamed entirely for their illness and accused of ‘choosing’ to remain unwell because they are supposedly ‘enjoying the sick role’ too much (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.a. [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 ‘therapy’ and this is often far more detrimental to children as compared to adults. As M.E. authors Verillo and Gellman explain:

Misdiagnosing [M.E.] as school phobia, depression, or separation anxiety or chalkling it up to family problems places the blame squarely on the shoulders of he child. When adults experience this kind of scepticism, they usually
are able to defend themselves against the mistaken ideas of others. Children are unable to do so; they depend on adults for information, explanations, sympathy and advice. 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).

The rate of clinical depression seen in M.E. is similar to, and not higher than, that seen in comparable illnesses such as rheumatoid arthritis. (Of course, depression is a common disease, and it does not make you immune from other diseases. So some patients with depression will also end up having other conditions as well, over time. This includes M.E., plus MS and Parkinson’s and all other diseases.) Feelings of sadness and grief in M.E. are caused by the loss of health, lifestyle, social role and financial means as well as the social stigma and severe abuse and neglect from friends and family and the medical profession that is so often an inescapable part of having M.E. (Stein 2005, [Online]).

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 (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 (Hooper et al. 2001, [Online]).

Although a minority of M.E. patients will have a clinical depression, more often some patients are instead dealing with natural and expected levels of grief and sadness for what they have lost. If these feelings are present, they are not evidence of a psychiatric disease but simply is a normal and healthy reaction to an extremely distressing life experience and extreme levels of physical suffering. The only ‘treatment’ needed is an improvement in the severity of the condition, and in many cases probably also greater levels of appropriate medical, financial and/or social support. As one longtime M.E. sufferer explained, ‘The desperation one gets periodically from being so ill is not at all the same thing as ‘clinical depression’. Give me an even somewhat better day physically – and my mood improves quickly and dramatically!’

- For more information about forced exercise and other ‘treatments’ used on M.E. children and adults (which have in some cases resulted in death) see: What is Myalgic Encephalomyelitis? Extra extended version

This medically unsupportable and abusive form of CBT can undoubtedly cause significant psychological harm, but it is these additional associated burdens; physical relapse lasting months, years or longer, the risk of death through overexertion in some severely affected patients, 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).

Clearly, CBT and GET are at best useless and at worst extremely harmful for M.E. patients. M.E. is not a short-term or ‘hit and run’ viral attack; it is not a self-limiting post-viral fatigue syndrome caused by mononucleosis/glandular fever, Q fever or hepatitis, or any other common infection. Nor is M.E. a psychological or behavioural condition, or a problem of mere ‘chronic fatigue’ or deconditioning. M.E. is also not medically unexplained, or the same thing as ‘CFS.’ M.E. cannot be improved through psychotherapy or graded exercise therapy. These theories have been comprehensively disproven many times over with regard to authentic 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). 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. Enough people with M.E. have had their long-term quality of life destroyed – or have been killed – by inappropriate use of these interventions.

If any drug caused even a very small percentage of the devastation GET causes in M.E. patients – let alone that it also had a zero percent chance of success – it would be immediately recalled. It would be an enormous worldwide scandal, and there would be some form of inquiry and serious criminal charges may well be laid. Yet the rate of people with M.E. recommended or even forced to exercise continues to rise, and with the full support of government, the mainstream medical community and the media.

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This is despite the fact that legitimate research and evidence clearly shows that it has a ZERO percent chance of providing any benefit to people with authentic M.E. Patients with M.E. are regularly coerced or forced to undertake a huge level of risk, including significant risk of death or severe long-term disablement and permanent damage, for zero chance of any gain. All because of financial vested interests controlling science, and completely different mixed patient groups being used to determine the treatments appropriate for an entirely different and unrelated homogenous patient groups.

That this can be allowed to happen in such a supposedly enlightened day and age as ours defies belief: It amounts to legalised medical torture and horrific long-term abuse of some of our most vulnerable members of society.

People with M.E. must again be treated as is ethically and scientifically appropriate, and not merely in a way designed to suit certain political and financial considerations. What is happening today to people with Myalgic Encephalomyelitis is a gross violation of basic human rights. This has to stop, it has to BE stopped.

For more information:

- See the paper Smoke and Mirrors for information on why patients with M.E. are being treated based on theories motivated by financial and political considerations rather than the available medical evidence. 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 print or save a copy of this text (or the entire database) in a printer-friendly Word or PDF format, see the Downloads section. A shorter/condensed version of this text is also available: The effects of CBT and GET – Condensed.

- See What is Myalgic Encephalomyelitis? A historical, political and medical overview 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 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 learn more about the extreme limits imposed on M.E. patients see: Why patients with severe M.E. are housebound and bedbound.

- 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:

3. 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.

4. 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

- For more information on scams aimed at M.E. patients (similar to CBT) such as the Lightning process, Reverse therapy, Mickel therapy, EFT and so on, see Comments on the ‘Lightning Process’ (etc.) scam page.

- 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.

Additional notes on this text:
- A note about antidepressant drugs and M.E.: Along with CBT and GET, antidepressants are another treatment also commonly recommended to M.E. patients based on evidence involving non-M.E. patient groups and produced by vested interest groups. M.E. patients are commonly recommended or verbally forced to take these drugs on what amounts to a random basis medically. As with CBT and GET, patients are almost always incorrectly told that these drugs are a safe and effective treatment for M.E. So what effect do these drugs have on Myalgic Encephalomyelitis patients?

  As with CBT and GET, they cannot improve the core problems of M.E. and can also very commonly cause serious adverse reactions. The number of M.E. patients that cannot tolerate these drugs, and for whom these drugs cause a worsening of the condition (including serious cardiac events) is very high. This is explained in more detail in the new paper: The effects of antidepressants on Myalgic Encephalomyelitis patients. (This paper is due to be completed late 2009)

What can you do to help?
People with Myalgic Encephalomyelitis have only a tiny minority of the medical, scientific, legal and other potentially supporting professions – or the public – on their side. What is needed is people from all over the world to stand up for Myalgic Encephalomyelitis – whether they are affected yet by M.E. or not. That is the only way change will occur, through education and people simply refusing to accept what is happening any more. This appalling abuse and neglect of so many severely ill people on such an industrial scale is truly inhuman and has already gone on for far too long. People with M.E. desperately need your help. See What is Myalgic Encephalomyelitis? and 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 see the References page.

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This paper will be continue to be updated regularly (at least annually). Please check back at the website periodically to make sure that you have the most up-to-date version of this paper available.
‘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 Malcolm 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-al-gic, 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. It has an UNIQUE Neuro-hormonal profile.’
Dr Elizabeth Dowsett

‘Deaths are not anecdotal and are a matter of public record. Patients with Myalgic Encephalomyelitis are dying and [also] developing complications (known to be fatal) such as heart disease and cancer at considerably younger ages than the statistical norm. This is significant and needs to be looked into.’
Jill McLaughlin

‘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

‘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.’
Dr Melvin Ramsay on Myalgic Encephalomyelitis

‘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

‘What all this amounts to is that we have lost any semblance indeed any pretence of pursuing scientific inquiry (into) what is true. This is almost classic in its near-phobic avoidance of considering anything that could possibly be construed as speaking the truth.’
Margaret Williams on Myalgic Encephalomyelitis

‘Never in the field of human illness have so many been betrayed by so few’
RiME Sept. 2007

‘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
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?

Professor Hooper 2007

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.
An excerpt:

Section 3: ON THE PATTERN/CAUSE OF SYMPTOM EXACERBATIONS, RELAPSES, AND DISEASE PROGRESSION IN MYALGIC ENCEPHALOMYELITIS

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

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

A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels post-M.E.
B. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.
C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient’s pre-illness tolerances and abilities.
E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.
G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.
H. The activity limits of M.E. are not short term: a gradual (or sudden) increase in activity levels beyond a patient’s individual limits can only cause relapse, disease progression or death in patients with M.E.
I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion; there is also a base level of illness which can be quite severe even at rest.
J. Repeated overexertion can harm the patient’s chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
K. Not every M.E. sufferer has ‘safe’ activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected.

A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels post-M.E.

Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is very common – if not universal – in Myalgic Encephalomyelitis. (Although a small percentage of sufferers may possibly be somewhat less severely affected at onset.) This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change. The onset of M.E. is frequently very dramatic, M.E. patients can very often tell you not just the day that they became ill, but the exact hour they became ill.

- M.E. can commonly be diagnosed within just a few weeks if the doctor has experience with M.E. (If all tests are normal, M.E cannot be the correct diagnosis.) See: Testing for M.E. for more information. For more information on the viral infection evident at onset in people with M.E., and the outbreaks of M.E. etc. see: The outbreaks (and infectious nature) of M.E.
M.E. is an acute onset illness, however it should be noted that: (a) some sufferers will be unsure of their onset type (they may not recall it, or may not recall it accurately, for various reasons) and (b) in some cases, acute onset M.E. is preceded by a series of unrelated minor infectious episodes (in a previously well patient) which may be misinterpreted as being a gradual onset of the M.E. (These minor infectious episodes may be due to the immune system being under temporary or chronic stress from events such as; recent immunisation, repetitive contact with a large number of infectious persons, or the effect of travel; as in exposure to a new subset of virulent infections. This pre-existing temporary or chronic immune system weakness is not seen in all patients and is not what causes M.E., although a compromised immune system will of course make the body more vulnerable to all types of infections, including M.E.)

B. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.

The bodies of people with Myalgic Encephalomyelitis respond inappropriately to anything that forces the body to have to react in some way or work harder in some way, in order to maintain internal homeostasis, including (but not limited to): physical activity, cognitive exertion (including emotional stress), sensory input and orthostatic stress. It should also not be assumed that a person with M.E. will necessarily react more severely to (or have greater limits on) physical activity than with cognitive exertion, sensory input or orthostatic stress. Some patients find that their most severe relapses come from orthostatic stress, while others will have to be more careful with their levels of sensory input or cognitive exertion as compared to physical activity. Other patients may be equally limited with each of these activities or stimuli, and so on. It varies from patient to patient and can also change over the course of the illness.

One of the main misconceptions about M.E. 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.

What is Homeostasis? Homeostasis is the ability of a living organism to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated self-regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits. M.E. causes a loss of the ability of the CNS (the brain) to adequately receive, interpret, store and recover information which would enable it to control vital body functions. There is a loss of normal internal homeostasis; the individual can no longer function systemically within normal limits.

Metabolic problems at a cellular level also contribute to this inability to maintain homeostasis in M.E. M.E. expert Dr Byron Hyde explains, ‘In MRI spectography of arm muscle of M.E. patients, it has been shown that because of an abnormal build-up of normal metabolites, the muscle cell actually shuts down to prevent cell death.’ This is what is happening to the M.E. patient’s cell physiology in every muscle (including the heart) and in the brain as a result of physical and cognitive activity and/or overexertion; there is ‘cell field shutdown’ to prevent the death of the cell. See: Treating Myalgic Encephalomyelitis - Avoiding Overexertion for more information and for references.

Physical activity in this context does not just mean aerobic exercise; it includes any physical movement or activity, including stretching and even very small movements. Cognitive activity refers to any type of thinking, or mental processing. Sensory input includes exposure to light, noise and movement etc. Orthostatic stress or postural stress includes sitting or standing, but also things like having a few pillows under your head when lying down or sitting up in bed; orthostatic stress is caused by any posture other than lying down flat (perhaps with legs raised to reduce the load on the heart; unless the patient is wearing pressure stockings, which achieve the same goal.).

C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.

When a person with M.E. is active beyond their individual post-illness limits, the result is not tiredness, fatigue or even exhaustion – nor is ‘malaise’ an accurate word to describe what occurs. There simply is no one symptom caused by overexertion in M.E. What does happen is that there is a worsening of all sorts of different symptoms and of the severity of the illness generally with overexertion. (Repeateed or severe overexertion can also cause
disease progression, permanent damage (eg. to the heart), or death in M.E.) It is an entirely different problem of a much greater magnitude.

Overexertion causes an exacerbation of all sorts of combinations of neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms which can be mild, moderate, severe, or even life threatening (eg. seizures and cardiac events). Many of the symptoms involved are present at a lower level at rest, but overexertion causes them to worsen. (Although some patients may also have some symptoms that only appear after overexertion.)

The types of symptoms produced in response to certain levels of physical activity, cognitive activity, sensory stimuli or orthostatic stress may or may not vary depending on the type (and severity) of the activity or stimuli involved. But very often the types of symptoms worsened or produced by overexertion are fairly similar regardless of which exertion or input was involved. Overexertion can sometimes cause just one or two symptoms to worsen (eg. cardiac problems) but often a large cluster of symptoms are worsened. The cluster of symptoms made worse by excessive exertion or stimulus is often very similar from patient to patient, as generally it is a worsening of the most common symptoms of the illness. Patients commonly experience a combination of the following symptoms:

- Profound cognitive dysfunctions (and various other neurological disturbances), muscle weakness (or paralysis), burning eye pain or burning skin, subnormal temperature or low-grade fever, sore throat or painful lymph nodes (and/or other signs of inappropriate immune system activation), faintness, weakness or vertigo, loss of coordination, dyspnea, an explosion of sensory phenomena (low level seizure activity), cardiac and/or blood pressure disturbances, facial pallor and/or a slack facial expression, widespread severe pain, nausea or feeling as if ‘poisoned,’ feeling cold and shivering one minute and hot and sweating the next, anxiety or even terror (as an organic part of the attack itself rather than as a reaction to it) and hypoglycaemia. Often the patient will feel an urgent need to retreat from all homeostatic pressures. The types of symptoms triggered vary widely from patient to patient, but some combination of these is common. There may also be an accompanying exacerbation of other symptoms. These symptoms often combine to create an indescribable and overwhelming experience of terrible illness that is unique to M.E, and can be profoundly incapacitating. At its most severe, the patient feels as if they are about to die.

Each of the symptoms caused or exacerbated by overexertion can be clearly articulated without difficulty whether they be; seizures, cardiac events, labile blood pressure, tachycardia, shortness of breath, muscle pain, muscle weakness or muscle paralysis, facial paralysis, black outs, flu-like symptoms, nausea, inability to speak or to understand speech, problems with memory, and so on. It makes no scientific or logical sense to subsume these very specific symptoms, and very specific and varied combinations of symptoms, under a vague and inaccurate label of mere ‘fatigue.’ To say that all of these very different and very specific – and in some cases very serious – symptoms can be accurately summarised as being a problem of mere ‘fatigue,’ ‘malaise’ or ‘exhaustion’ is absurd.

- A large number of illnesses cause significant fatigue or malaise after activity (for example post-mononucleosis or glandular fever fatigue syndromes, Lyme disease and Fibromyalgia and so on) but what is happening in M.E. is simply not the same; the symptomatology and pathology – and the effect of physical, cognitive and orthostatic overexertion on long-term prognosis – is very different in M.E.
- Also note that: repeated or severe overexertion can also cause disease progression, permanent damage (eg. to the heart), or death in M.E. patients. Again, to suggest that these very serious and long-term effects – and fatalities – could be accurately summarised as being a problem of mere ‘fatigue’ is clearly absurd
- An additional note on ‘fatigue’: The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, muscular, gastrointestinal and other symptoms and characteristics (and so on) – the presence or absence of mere ‘fatigue’ is irrelevant. In addition to these other (far more serious) symptoms, some M.E. sufferers may also suffer with mild, moderate or severe fatigue some of the time, while others will not. Thus the symptom of fatigue is not an essential symptom of M.E. and does not define M.E. (Although the symptom of fatigue is essential to qualify for a misdiagnosis of ‘CFS’). For more information see: M.E. is not defined by ‘fatigue’ and The misdiagnosis of CFS. The point to be most aware of is that M.E. is ‘more than fatigue’ – but that M.E. ISN’T FATIGUE AT ALL.

D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient’s pre-illness tolerances and abilities.

When there is talk of ‘overexertion’ leading to an exacerbation of symptoms in M.E. what is being referred to is not hard exercise, it is not anything resembling what healthy people would recognise as ‘overexertion.’ This term just refers to any activity which goes beyond a person’s individual post-M.E. limits.

There is a lot of variation from patient to patient but very often the levels of activity required to cause relapse are trivial compared to a patient’s pre-illness tolerances and abilities. For example, what constitutes overexertion for someone with severe M.E. could be something as small as rolling over in bed, walking or talking for a few...
minutes, or eating a meal. The severity and duration of relapses varies depending on the severity of a person’s illness, but relapses in M.E. are very often way out of all proportion to the actual activity. Relapses can be very severe and prolonged (or even permanent) even if a person with M.E. has only gone past their individual limits in a seemingly minor way.

- **A note on M.E. and other illnesses:** This extreme and out of all proportion reaction to even trivial levels of activity is just not seen in those illnesses causing fatigue (and other symptoms) after exertion which may commonly be misdiagnosed as ‘CFS.’ People with post-viral fatigue syndromes, Fibromyalgia and Lyme disease etc. are not affected by small activities for many weeks, months, or permanently, in this way. While people with M.E. and people with these other illnesses may all not improve with a graded exercise regime, the way people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress is profoundly different than in these other illnesses. The two problems are quite distinct.

E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.

One can probably observe people with some illnesses carefully for an hour or so and collect a lot of good information about what they can and can’t do, how severe their illness is, and what their usual symptoms are from day to day, and so on. However M.E. is not one of those illnesses. M.E. is *not* a stable illness.

Observing the average M.E. sufferer for an hour – or even a week or more – will not give an accurate indication of their usual activity level because the severity of M.E. can wax and wane throughout the month, week, day and even hour. Also, people with M.E. can sometimes operate significantly above their actual illness level for short periods of time thanks to surges of adrenaline – albeit at the cost of severe and prolonged worsening of the illness afterward. Relapses and worsening of symptoms are also very often also significantly delayed (there may be both an acute AND a delayed reaction).

Just observing someone with M.E. do a certain task should not be taken to mean (a) that they can necessarily repeat the task anytime soon, (b) that they would have been able to do it at any other time of day, (c) that they can do the same task every hour, day or even every week, or month, or (d) that they wont be made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task. Often a considerable rest period is needed before and after a task, which may be hours, days, weeks or months long. For example, someone may need 2 weeks rest before an outing, for example, and may then spend 3 weeks extremely ill afterwards recovering from it. Just observing them in the 2 hours they were ‘out and about and mobile’ is of course not at all representative of their usual ability levels.)

Most importantly, because the worsening of the illness caused by overexertion may not even begin until 48 or more hours afterwards (when most observers are long gone), it’s impossible to tell by seeing an M.E. patient engaged in an activity, whether that activity is so far beyond the patient’s limits that it will end up causing a severe or even permanent worsening of the illness (or ‘relapse’). To be blunt, the activity may even end up killing the patient. This isn’t common (the death rate is estimated at 3%), but deaths can and do occur. Thus, observers who see an M.E. patient engaged in an activity have no idea what the consequences of this activity may be.

- **What is an adrenaline surge?** Adrenaline is often referred to as the ‘fight or flight’ hormone as it kicks into action in situations of potential danger. However, adrenaline also kicks in when the body is in physiological difficulty, which is very often what is happening to severe M.E. sufferers. Adrenaline surges make the heart pump faster and raise the blood pressure, forcing blood around the body with greater force to supply the muscles with more oxygen, so that they can make a greater effort. Surges of adrenaline increase the metabolism. They also relax and dilate the airways so that more oxygen than usual can be taken in. Adrenaline surges can also decrease the amount of pain felt. As a result of all of these factors, adrenaline surges – while they last – have the ability to increase physical speed, strength and other physical abilities.

  Unfortunately, when these bursts of adrenaline wear off – as they must – people with M.E. are left far more ill as a result for many days, weeks, months or even years. People with M.E. are harmed by adrenaline surges, both by the physiological stress to the body of the changes caused by adrenaline, and by the extra activity which adrenaline enables, which may be far beyond the body’s normal limits so that such activity causes damage. For every short term ‘gain’ there is a far greater loss overall.

  For more information on adrenaline surges in M.E., and the different order in which certain bodily systems may be affected by M.E. (and by overexertion), see the Dr Cheney section in *The effects of CBT and GET on patients with Myalgic Encephalomyelitis* or *Treating Myalgic Encephalomyelitis - Avoiding Overexertion*.

- **A note on M.E. and other illnesses:** This is another one of the characteristics which clearly differentiates authentic M.E. from various self-limiting post-viral fatigue syndromes and so on – the striking variability of symptoms not only in the course of a day but often within the hour. As many M.E. experts have noted, this variability of the intensity of the symptoms is simply not found in post-viral fatigue states or syndromes (etc).

- There is also a waxing and waning of the *physical signs* of M.E. throughout the day, as Dr Hyde and Dr Jain explain, “A patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day.”

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F. The worsening of the illness caused by overexertion can be acute, but often does not reach its peak until 24 - 72 hours (or more) later.

Another reason that short-term and superficial judgements of ability and disability levels in people with M.E. are ill-advised and often very misleading – and are in fact almost guaranteed to give a falsely more optimistic view of daily ability levels – is because the relapses caused by exertion very often do not appear until 48 or more hours afterward, when the average observer is long gone.

The onset of the worsening of symptoms caused by overexertion is sometimes be acute but often will not peak until 48 hours or more afterward (this is particularly true with regard to physical, cognitive and orthostatic exertions). Symptoms will then persist for hours, weeks or many months, or longer. For many M.E. sufferers, the effects from significant overexertion will very often peak on day three.

Sometimes there is a significant worsening of symptoms evident at the time of overexertion. At other times, there may only be a minor worsening of symptoms at the time of overexertion, but the delayed effects will be severe. Sometimes the acute effects and the delayed effects will both be severe. It varies depending on the type and severity of the overexertion involved etc.

- A note on M.E. and other illnesses: The ‘CFS’ definitions state that post-exertional symptoms ‘may take up to 24 hours to resolve.’ But to say that this is true of M.E. patients betrays an ignorance of the most basic facts of M.E. Post-exertional symptoms very often take far longer than 24 hours to even APPEAR in people with M.E., let alone be completely resolved in that time. These symptoms can take days, weeks, months or even several years to resolve. Overexertion can also cause a worsening of the base level of illness in M.E. and so the effects of overexertion can also be semi-permanent or permanent. Death can also occur due to overexertion in M.E.

This significant delay in the onset of post-exertional symptoms is not seen in those illnesses causing fatigue (etc.) after exertion. Nor do the effects of even minor overexertion very often last for weeks, months, years or permanently in people with these various fatigue syndromes as they do with M.E. sufferers. There is also not the same risk of overexertion leading to death in these other illnesses, as there is with M.E (The cardiac insufficiency seen in M.E., which causes much of the symptomatology and the limits with activity and orthostatic stress and so on in M.E., is simply not seen in these other illnesses.)

G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.

In addition to the effects of overexertion commonly being delayed by 48 hours or so, the worsening of symptoms caused by overexertion can also sometimes be delayed (and accumulate) over weeks or even many months at a time until they are realised in a ‘crash.’ This is a period of intense worsening of the overall condition followed by a gradual return to the patient’s base level of illness over weeks, months or even years.

When the body is confronted with activity (or inputs) beyond the patient’s individual limits severely and/or repeatedly over time, these effects can also become cumulative in the long term; the patient becomes unable to return to their base level of illness at all. What this means is that long-term or permanent worsening of the overall severity of the condition is caused. Thus some patients are still dealing with the severe physical effects of inappropriate advice to exercise or to be more physically or mentally active etc. five, ten, fifteen or more YEARS afterward and for some patients the damage caused is permanent. Overexertion has also resulted in death in some cases of M.E.

Strong evidence exists to show that overexertion can have extremely harmful effects on M.E. patients. 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. (Recent research has shown that postural stress and physical and mental overexertion exacerbate cardiac insufficiency in this disease; see the notes below for more information.) In addition to the risk of relapse, permanent damage, and disease progression, there have also been reports of sudden deaths in M.E. patients following exercise. As M.E. expert Dr. Elizabeth Dowsett explains, ‘20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise. Prompt recognition and advice to avoid over-exertion is mandatory.’

- For more information on the question of “Can M.E. patients really die just from being forced out of bed, or to leave the house etc.?” please see the paper: Why patients with severe M.E. are housebound and bedbound

- Cardiac and vascular abnormalities have been documented from the earliest outbreaks of M.E. to the present day. Dr. Paul Cheney explains that when M.E. patients stand up, they are on the edge of organ failure as their cardiac output has dropped to the extremely low level of 3.7 litres per minute, a 50% drop from the normal output of 7 litres per minute. Without exception, says Cheney, every M.E. patient ‘is in heart failure.’

Recent research shows that mitochondrial and other dysfunction leads to diastolic dysfunction and reduced stroke volume/low cardiac output in M.E. – and that certain levels of orthostatic stress and physical and mental activity etc. exacerbate this cardiac insufficiency. Dr Cheney explained recently that because it takes more
metabolic energy for the heart to relax and fill with blood than it does for it to squeeze and pump blood, the hearts of people with M.E. don’t fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. (and much of the disability of M.E.). So the tachycardia – fast heart rate – often seen in M.E. in response to orthostatic stress and so on is actually compensating for low stroke volume to help increase cardiac output. The heart doesn’t fill with enough blood before each beat of the heart so it is forced to beat faster to try to make up some of the shortfall, but people with M.E. are still left with reduced cardiac output which leaves them very ill and disabled. If this problem is severe enough it can result in death.

As one M.E. advocate explains: ‘Cardiac output is sometimes too low to meet the demands of movement, and any attempt to exert oneself beyond one's own capacity for cardiac output - that is when demand exceeds cardiac capacity - would indeed result in death. Studies on dogs have shown that when the demands of the body exceed cardiac output by even 1%, the organism dies. M.E. patients [must] reduce demand and reduce their exertion level to stay within the bounds of their low cardiac output to stay alive.’

- **A note on M.E. and other illnesses:** It is sometimes claimed that while exercise programs are not safe or appropriate for the severely affected, that mild or moderately affected M.E. sufferers can benefit from such interventions. But this assertion is NOT supported by the evidence. (Some miscellaneous ‘fatigue’ sufferers have been shown to benefit from graded exercise programs, but the results of these studies are no more relevant to mild M.E. sufferers than they are to severe M.E. sufferers; people with ‘fatigue’ DO NOT have mild M.E. any more than they have mild multiple sclerosis, mild Lyme disease, mild cancer or any other illness.) Recent studies have shown that graded exercise programs are the actual reason many with M.E. are so severely affected in the first place, thus exercise programs should not be considered safe for M.E. sufferers of any severity. Graded exercise cannot improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E.

**H. The activity limits of M.E. are not short term, a gradual (or sudden) increase in activity levels beyond a patient’s individual limits can only cause relapse, disease progression or death in patients with M.E.**

Increasing the activity levels of someone with M.E. beyond their individual limits, can only ever be counterproductive. It really doesn’t matter if you do this gradually or all at once. Raising the limits gradually may well delay the onset of the relapse in some patients, but the end result will still be relapse and/or disease progression, or death. None of the various cardiac, cardiovascular, immunological, neurological, cognitive, muscular, and other abnormalities present in M.E. sufferers – which together cause the high level of disability associated with M.E. – can be explained by mere ‘deconditioning.’ **Patients who improve with graded activity programs do not qualify for a diagnosis of M.E.**

- M.E. is not a short-term or ‘hit and run’ viral attack; it is not a self-limiting post-viral fatigue syndrome caused by mononucleosis/glandular fever, Q fever or hepatitis, or any other common infection. Nor is M.E. a psychological or behavioural condition. Authentic M.E. cannot be improved through psychotherapy or graded exercise therapy. These theories have been comprehensively disproven many times over with regard to authentic M.E. patients (as have the many other similar theories). M.E. is a chronic illness which affects the vast majority of sufferers for many years or decades at a time, or for the rest of their lives. A person who has been correctly diagnosed with M.E. will naturally raise their activity levels when/if they have had an improvement in their illness – but it can never work the other way around. See: Smoke and mirrors for more information.

- **A note on M.E. and other illnesses:** M.E. can be progressive, degenerative, chronic, or relapsing and remitting. As many M.E. experts have noted, the chronicity of M.E. is another characteristic which clearly separates the illness from various self-limiting post-viral fatigue syndromes.

**I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion, there is also a base level of illness which can be quite severe even at rest.**

There is a base level of illness that is always present in M.E., even at rest. (This is true of all sufferers except perhaps that small percentage who have improved enough over time to be only mildly affected, or who have had a total or almost total remission of their M.E.) This is because the metabolic problems of M.E. are only one part of M.E., they are not the only cause of symptoms or of the worsening of the illness.

But even those symptoms which are caused by the metabolic problems of M.E. (etc.) do not always resolve with rest. For severely affected patients, just keeping the body going at the lowest possible level can count as ‘overexertion’ – not only can the bodies of these people not cope with extra activity, but they also cannot even cope with keeping the bodily systems and organs going at the lowest possible level – at rest. Because even when we are resting as much as we can be; hearts have to keep pumping, lungs have to keep drawing air in and out constantly, kidneys have to keep working, and so on. It takes a lot of metabolic power to keep all the complex systems in the body working, even at the lowest possible level. Forcing the body to do more work when it is already not coping with the most basic level of functioning causes these problems to become even more severe as the quality of function achieved across various bodily systems is lowered even further, but even at rest these same problems can be quite severe because of course so many different bodily systems never can ‘rest.’

Virtually all bodily systems are affected in some way by both the damage to the central nervous system and the metabolic problems of M.E. (including the cardiac insufficiency this causes) etc. so it is no wonder people with
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M.E. feel so ill, have such a reduced level of functioning in so many different bodily systems and have so many restrictions and limits on how active they can be. Even with complete rest – and some people with M.E. can do almost nothing else – many M.E. sufferers are still very ill and disabled.

J. Repeated overexertion can harm the patient’s chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.

It is vital that M.E. patients are never encouraged to be active beyond their individual limits. As Dr Melvin Ramsay explains; ‘The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.’

Patients with M.E. must be allowed to determine for themselves a level of daily activity which is not needlessly restrictive, but which is also sustainable in the long term without causing a worsening of symptoms or disease progression (and which also holds back a small amount of ability to cope with occasional unplanned or unavoidable overexertions, to prevent these from causing significant setbacks). People with M.E. must also be allowed to determine for themselves how much rest they need. Giving people with M.E. the support they need to limit their activities in this way is actually the best way to ensure that they each get to be as active as possible in the long term. The importance of getting appropriate rest and avoiding overexertion in M.E. cannot be overstated.

For more information about the effects of overexertion on M.E. patients, including statements/research from some of the world’s leading M.E. experts about why overexertion is so physically harmful, see: Smoke and Mirrors. (This paper also includes links to many different patient accounts of the effects of overexertion on people with M.E.). If you have M.E. see Treating Myalgic Encephalomyelitis - The Basics and Treating Myalgic Encephalomyelitis - Avoiding Overexertion for more on the importance of avoiding overexertion.

L. Not every M.E. sufferer has ‘safe’ activity limits within which they will not exacerbate their illness, this is not the case for the very severely affected.

For very severely affected M.E. sufferers there is virtually no ‘safe’ level of physical or mental activity, orthostatic stress or sensory input; no level which does not produce a worsening of symptoms, and perhaps also contribute to disease progression. Even the most basic actions – speaking a few words, being exposed to moderate light or noise for a few minutes, turning over in bed, having hair or body washed in bed by a carer or chewing and swallowing food – cause severe and extended symptom exacerbations in such patients. It is not uncommon to hear of very severely affected sufferers who are unable to bathe themselves (or even be bathed by a carer) more often than once a week, or even once every few weeks, or even less. Some sufferers cannot chew or swallow food any longer and need to be tube fed. Many patients with severe M.E. are no longer able to toilet themselves, and so on. Either sufferers are just too ill to do these things at all, or they cannot tolerate the very long and severe relapses that come after such activities.

Even the smallest movement, thought, touch, light, noise or period upright etc. can the already very severe symptoms far, far worse. Thus few illnesses demand such isolation and loss of quality of life as severe M.E. Very often people with very severe M.E. can barely communicate, or even tolerate the presence of another person. This is what makes M.E. such a cruel disease and such an isolating disease. The illness can cause a level of disability and isolation that is just unimaginable to anyone not familiar with very severe M.E.

For more information on severe M.E. see The severity of M.E. and M.E. Fatalities plus Why patients with severe M.E. are housebound and bedbound.

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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 world's 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.
A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy

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
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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 AiME 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.

www.hfme.org
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.

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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 homeostasis. 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
Myalgic Encephalomyelitis (M.E.) is a debilitating acquired neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder with the code G.93.3. M.E. can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934. M.E. is similar in a number of significant ways to multiple sclerosis, Lupus and poliomyelitis (polio). M.E. can be extremely severe and disabling and in some cases the disease is fatal.

Is Myalgic Encephalomyelitis a new illness? What does the name M.E. mean?
The illness we now know as Myalgic Encephalomyelitis is not a new illness. M.E. is thought to have existed for centuries. (Hyde 1998, [Online]) (Dowsett 1999a, [Online])

In 1956 the name Myalgic Encephalomyelitis was created. The term was invented jointly by Dr A Melvin Ramsay who coined this name in relation to the Royal Free Hospital epidemics that occurred in London in 1955 - 1957 and by Dr John Richardson who observed the same type of illness in his rural practice in Newcastle-upon-Tyne area during the same period. It was obvious to these physicians that they were dealing with the consequences of an epidemic and endemic infectious neurological disease (Hyde 1998, [Online]) (Hyde 2006, [Online]). The term Myalgic Encephalomyelitis means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation (Hyde 2006, [Online]). As M.E. expert Dr Byron Hyde writes:
The reason why these physicians were so sure that they were dealing with an inflammatory illness of the brain is that they examined patients in both epidemic and endemic situations with this curious diffuse brain injury. In the epidemic situation with patients falling acutely ill and in some cases dying, autopsies were performed and the diffuse inflammatory brain changes are on record (2006, [Online]).

In 1957, the Wallis description of M.E. was created. In 1959 Sir Donald Acheson (a former UK Chief Medical Officer) conducted a major review of M.E. In 1962 the distinguished neurologist Lord Brain included M.E. in the standard textbook of neurology. In recognition of the large body of compelling research that was available, M.E. was formally classified as an organic disease of the central nervous system in the World Health Organisation’s International Classification of Diseases in 1969 with the code G.93.3 In 1978 the Royal Society of Medicine held a symposium on Myalgic Encephalomyelitis at which M.E. was accepted as a distinct entity. The symposium proceedings were published in The Postgraduate Medical Journal later that same year. The Ramsay case description of M.E. was published in 1981 (Hooper et al. 2001, [Online]).

Since 1956 the term Myalgic Encephalomyelitis has been used to describe the illness in the UK, Europe Canada and Australasia. This term has stood the test of time for more than 50 years. The recorded medical history of M.E. as a debilitating organic neurological illness affecting children and adults is substantial; it spans over 70 years and has been published in prestigious peer-reviewed journals all over the world (Hyde 1998, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001b, [Online]). As microbiologist and M.E. expert Dr Elizabeth Dowsett explains: ‘There is ample evidence that M.E. is primarily a neurological illness, although non-neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised’ (n.d.b, [Online]).

Myalgic Encephalomyelitis is not defined by mere ‘fatigue’
Myalgic Encephalomyelitis is not synonymous with being tired all the time. If a person is very fatigued for an extended period of time this does not mean they are having a ‘bout’ of M.E. To suggest such a thing is no less absurd than to say that prolonged fatigue means a person is having a ‘bout’ of multiple sclerosis, Parkinson’s disease or Lupus. If a person is constantly fatigued this should not be taken to mean that they have M.E. no matter how severe or prolonged their fatigue is. Fatigue is a symptom of many different illnesses as well as a feature of normal everyday life – but it is not a defining symptom of M.E., nor even an essential symptom of M.E.

The terms ‘fatigue’ and ‘chronic fatigue’ were not associated with defining this illness at all until the new name (and definition) of ‘Chronic Fatigue Syndrome’ was created in 1988 in the USA (Hyde 2006, [online]). But M.E. and CFS are not synonymous terms.
‘Fatigue’ and feeling ‘tired all the time’ are not at all the same thing as the very specific type of paralytic muscle weakness or muscle fatigue which is characteristic of M.E. (and is caused by mitochondrial dysfunction) and which affects every organ and cell in the body; including the brain and the heart. This causes – or significantly contributes to – such problems in M.E. as; cardiac insufficiency (a type of heart failure), orthostatic intolerance (inability to maintain an upright posture), blackouts, reduced circulating blood volume (and pooling of the blood in the extremities), seizures (and other neurological phenomena), memory loss, problems chewing/swallowing, episodes of partial or total paralysis, muscle spasms/twitching, extreme pain, problems with digestion, vision disturbances, breathing difficulties, and so on. These problems are exacerbated by even trivial levels of physical and cognitive activity, sensory input and orthostatic stress beyond a patient’s individual limits. People with M.E. are made very ill and disabled by this problem with their cells; it affects virtually every bodily system and has also lead to death in some cases. Many patients are housebound and bedbound and often are so ill that they feel they are about to die. People with M.E would give anything to instead only be severely ‘fatigued’ or tired all the time (Bassett 2009, [Online]).

Fatigue or post-exertional fatigue (or malaise) may occur in many different illnesses such as various post-viral fatigue states or syndromes, Fibromyalgia, Lyme disease, and many others – but what is happening with M.E. patients is an entirely different (and unique) problem of a much greater magnitude. These terms are not accurate or specific enough to describe what is happening in M.E. M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of ‘chronic fatigue’ (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d., [Online]).

For more information see Myalgic Encephalomyelitis is not fatigue, or ‘CFS’. Many of the worlds leading M.E. experts have spoken out strongly against ‘fatigue’ being claimed to be the defining/essential symptom of M.E. see M.E. is not defined by ‘fatigue’ to read some of their comments.

For more information on the symptoms of M.E., including the unique reaction people with M.E. have to activity (etc.), see: The ultra-comprehensive Myalgic Encephalomyelitis symptom list

If Myalgic Encephalomyelitis and ‘Chronic Fatigue Syndrome’ are not synonymous terms, why do some groups claim that they are? What is CFS?
The disease category of CFS was created in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not exist.

Why 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). 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.

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). As Dr Elizabeth Dowsett comments, these ridiculous financially motivated theories bear as much relation to legitimate science ‘as Astrology does to Astronomy’ (1999b). Professor Malcolm Hooper goes on to explain:

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

Members of the ‘Wessely school’ in the UK including Wessely, Sharpe, Cleare and White, their US counterparts Reeves, Straus etc of the CDC, in Australia Lloyd, Hickie etc and the clinicians of the Nijmegen group in the Netherlands each support a bogus psychiatric or behavioural paradigm of ‘CFS’ and recommend rehabilitation-based approaches such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as the most useful interventions for ‘CFS’ patients. It is important to be aware that none of these groups is studying patients with M.E. Each of these groups uses a definition of ‘CFS,’ or has created their own, which does not select those with M.E. but instead selects those with various types of psychiatric and non-psychiatric fatigue. (These inappropriate interventions are at best useless and at worst extremely harmful or fatal for M.E. patients.)

The creation of the bogus disease category ‘CFS’ has undoubtedly been used to impose a false psychiatric paradigm of M.E. by alloying it with various unrelated psychiatric fatigue states and post-viral fatigue syndromes (etc) 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]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]).

To read about the vast difference between M.E. and CFS (and how such a small (but powerful) group of vested interest psychiatrists have come to influence the opinions of the worldwide medical community about M.E.) see: Who benefits from ‘CFS’ and ME/CFS? and Smoke and mirrors and also A Brief History of Myalgic Encephalomyelitis & An Irreverent History of CFS by Dr Byron Hyde

What does a diagnosis of ‘Chronic Fatigue Syndrome’ actually mean?

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


Under the cover of ‘CFS’ certain vested interest groups have assiduously attempted to obliterate recorded medical history of Myalgic Encephalomyelitis; even though the existing evidence has been published in prestigious peer-reviewed journals around the world and spans over 70 years. 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]).

The only way forward for M.E. patients and all of the diverse patient groups commonly misdiagnosed with ‘CFS’ (both of which are denied appropriate support, diagnosis and treatment, and may also be subject to serious medical abuse) is that the bogus disease category of 'CFS' must be abandoned. Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery and this process must begin with a correct diagnosis if at all possible. A correct diagnosis is half the battle won (Hyde 2006a, 2006b, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett n.d., [Online]).

- For more information on why the bogus disease category of 'CFS' must be abandoned see: Who benefits from 'CFS' and 'ME/CFS'? The misdiagnosis of CFS. Why the disease category of 'CFS' must be abandoned and Smoke and Mirrors.
- Those patients misdiagnosed with 'CFS' (and who do not have M.E.) are advised to read the following papers: The Misdiagnosis of 'CFS' and Where to after a 'CFS' (mis)diagnosis?
- An additional note on 'fatigue': Just as some M.E. sufferers will experience other minor and non-essential symptoms such as vomiting or night sweats some of the time, but others will not, the same is true of fatigue. The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms (and so on) – the presence or absence of mere ‘fatigue’ is irrelevant.

What do the terms CFIDS, ME/CFS, CFIDS/ME, Myalgic Encephalopathy and ME-CFS mean?
When the terms CFIDS, ME/CFS, CFIDS/ME, Myalgic Encephalopathy or ME-CFS are used it 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.

[www.hfme.org](http://www.hfme.org)
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.’) It is also important that the only terms which are used are those which do have an official and correct World Health Organization classification.

There is no such disease/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.

- For more information on the name Myalgic Encephalomyelitis (and the problems with some of these other terms including ME’opathy) see: Meitis? A slender string to our bow, Who benefits from ‘CFS’ and ‘ME/CFS’? The Terminology of ME & CFS, and ME and CFS, The Definitions. See On the name MEitis for more articles.

- For more information on why the bogus disease category of ‘CFS’ must be abandoned, (along with the use of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ ‘CFIDS’ and ‘Myalgic Encephalopathy’ and others), see: Who benefits from ‘CFS’ and ‘ME/CFS’? Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename ‘CFS’ as ‘ME/CFS’ and Problems with the use of ‘ME/CFS’ by M.E. advocates, plus The misdiagnosis of CFS. Why the disease category of ‘CFS’ must be abandoned and Smoke and Mirrors

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.

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.

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 does define Myalgic Encephalomyelitis? What is its symptomatology?

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 (Chabursky et al. 1992 p. 20) (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 pp. x-xxi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92).

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

What are some of the symptoms of Myalgic Encephalomyelitis?

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

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

Neurocognitive dysfunction may include cognitive, motor and perceptual disturbances. Cognitive dysfunction may be pronounced and may include; difficulty or an inability to speak (or understand speech), difficulty or an inability to read or write or to do basic mathematics, difficulty with simultaneous processing, poor concentration, difficulty with sequencing and problems with memory including; difficulty making new memories, difficulty recalling formed memories and difficulties with visual and verbal recall (eg. facial agnosia). There is often a marked loss in verbal and performance intelligence quotient (IQ) in M.E. (Bassett 2009, [Online]).

- For a more complete symptom list see: The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List
- See also: What it feels like to have M.E.: A personal M.E. symptom list and description of M.E.
- See Research and Articles for many hundreds of different articles and medical studies into M.E.

What other features define or characterise Myalgic Encephalomyelitis?
What characterises M.E. every bit as much as the individual neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. In other words, the pattern of symptom exacerbations, relapses and of disease progression.

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

L. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels post-M.E.
M. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.
N. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
O. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient’s pre-illness tolerances and abilities.

P. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
Q. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.
R. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.
S. The activity limits of M.E. are not short term: a gradual (or sudden) increase in activity levels beyond a patient’s individual limits can only cause relapse, disease progression or death in patients with M.E.
T. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion; there is also a base level of illness which can be quite severe even at rest.
U. Repeated overexertion can harm the patient’s chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
V. Not every M.E. sufferer has ‘safe’ activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected (Bassett 2009, [Online]).

- For the full-length version of this text and for a full list of references for this text see: The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List.

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

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

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

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

See: The outbreaks (and infectious nature) of M.E. section for more information.

What does cause Myalgic Encephalomyelitis? Are there outbreaks of M.E.?

One of the most fundamental facts about M.E. throughout its history is that it occurs in epidemics. There is a history of over sixty recorded outbreaks of the illness going back to 1934 when an epidemic of what seemed at first to be poliomyelitis was reported in Los Angeles. As with many of the other M.E. outbreaks the Los Angeles outbreak occurred during a local polio epidemic.

The presenting illness resembled polio and so for some years the illness was considered to be a variant of polio and classified as ‘Atypical poliomyelitis’ or ‘Non-paralytic polio’ (TCRME 2007, [Online]) (Hyde 1998, [Online]) (Hyde 2006, [Online]). Many early outbreaks of M.E. were also individually named for their locations and so we also have outbreaks known as Tapanui flu in New Zealand, Akureyri or Icelandic disease in Iceland, Royal Free Disease in the UK, and so on (TCRME 2007, [Online]) (Hyde 1998, [Online]).

A review of early M.E. outbreaks found that clinical symptoms were consistent in over sixty recorded epidemics spread all over the world (Hyde 1998, [Online]). Despite the different names being used, these were repeated outbreaks of the same illness. It was also confirmed that the epidemic cases of M.E., and the sporadic cases of M.E. each represented the same illness (Hyde 2006, [Online]) (Dowsett 1999a, [Online]).

M.E. is an infectious neurological disease and represents a major attack on the 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. The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling and Hyde, (and others) have all indicated that M.E. is caused by an enterovirus. The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling and Hyde, (and others) have all indicated that M.E. is caused by an enterovirus.

M.E. also cannot be caused by a period of long-term or intense stress, trauma or abuse in childhood, becoming run-down, working too hard or not eating healthily. Myalgic Encephalomyelitis is not a form of ‘burnout’ or nervous exhaustion, or the natural result of a body no longer able to cope with long-term stress.

Other researchers have also shown the link between M.E. and enteroviruses. For example, Dowsett (2001a, [Online]) (Dowsett et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Ryll 1994, [Online]) have all indicated that M.E. is caused by an enterovirus. The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling and Hyde, (and others) have all indicated that M.E. is caused by an enterovirus.

The US Centres for Disease Control (CDC) placed ‘CFS’ on its ”Priority One; New and Emerging" list of infectious diseases some years ago; a list that also includes Lyme disease, hepatitis C, and malaria’ (Gellman & Verillo 1997, p. 19). But no real research into transmissibility (or more importantly on reducing infection rates) has been done by any government on patients with M.E. (or ‘CFS’) despite ample evidence that this is an infectious disease. There have been many well-documented clusters or outbreaks of the illness, reports of as many as 4.5% of M.E. sufferers contracting the illness immediately after blood transfusions (or after needle-stick injuries involving the blood of M.E. patients), evidence of the disease spreading through casual contact amongst family members and so on (Johnson, 1996) (Carruthers et al. 2003, p.79).

See: The outbreaks (and infectious nature) of M.E. section for more information.
As Dr Elizabeth Dowsett explains: ‘The problem we face is that, in spite of overwhelming epidemiological and technical evidence of an infectious case, the truth is being suppressed by the government and the ‘official’ M.E. charities as ‘too scary’ for the general public.’ (n.d.a, [Online]) This pretence of ignorance on behalf of government worldwide has had enormous consequences; only in the UK are people with M.E. specifically banned from donating blood for example. So it is that the number of people infected with M.E. continues to rise unabated and largely unnoticed by the public (Johnson, 1996).

- See: The outbreaks (and infectious nature) of M.E. section for more information.

Is Myalgic Encephalomyelitis difficult to diagnose? What tests can be used to diagnose M.E.?

M.E. is a distinct, recognisable disease entity that is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease (within just a few weeks) – providing that the physician has some experience with the illness. There is just no other illness that is even remotely like M.E.

Although there is as yet no single test which can be used to diagnose M.E. there are (as with Lupus and multiple sclerosis and ovarian cancer and many other illnesses) a series of tests which can confirm a suspected M.E. diagnosis. Virtually every M.E. patient will also have various abnormalities visible on physical exam. If all tests are normal, if specific abnormalities are not seen on certain of these tests (eg. brain scans), then a diagnosis of M.E. cannot be correct (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hooper et al. 2001, [Online]) (Chabursky et al. 1992, p.22). As M.E. expert Dr Byron Hyde explains:

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


- See: Testing for M.E. for more information on the various tests which can aid M.E. diagnosis. See also: Are we just marking time?
- Objective scientific tests are available which can aid in the diagnosis of M.E. (and easily prove the severe abnormalities across many different bodily systems seen in M.E.), but unfortunately many patients are not given access to these tests. For more information on the lack of access to appropriate testing for M.E. patients see: The Montague/Hoope Paper

How common is Myalgic Encephalomyelitis? Who get M.E. and how?

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

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

M.E. has a similar strike rate to multiple sclerosis (or possibly somewhat higher), and is estimated to affect roughly 0.2% of the population. Children and teenagers are also susceptible to the illness and children as young as five have been diagnosed with M.E. (M.E. can occur in children younger than five, but this is thought to be rare.) All ages are affected but most commonly sufferers are under 45 at onset. Women are affected around three times as often as men, a ratio common in autoimmune disorders, although in children the sexes seem to be afflicted equally. M.E. affects all races and socio-economic groups and has been diagnosed all over the world. There are more than a million M.E. sufferers worldwide (Hooper et al. 2001 [Online]) (Hyde 1992, pp. x - xxi).
The CDC have recently released vastly inflated estimates for ‘CFS’ but it should be noted that the number of people suffering with mild fatigue has no more relevance to patients with M.E. to those with MS or AIDS or any other distinct illness. For more information see: More medical ‘firsts’ from the CDC?

Are there any treatments for Myalgic Encephalomyelitis?
Whilst there is no cure as yet, or treatments which can dramatically influence the course of the illness due to the appalling lack of funding into research; intelligent nutritional, pharmaceutical and other interventions can make a significant difference to a patient's life. Appropriate biomedical diagnostic testing should be done as a matter of course (and repeated regularly) to ensure that the aspects of the illness which are able to be treated can be diagnosed, monitored and then treated as appropriate. Testing is also important so that dangerous deficiencies and dysfunctions (which may place the patient at significant risk) are not overlooked (Hooper at al. 2001 [Online]). For information on treatment see: Treating M.E. - The Basics.

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

Many different organic abnormalities have been found in M.E. patients (in peer reviewed research). Patient advocates Margaret Williams and Eileen Marshall explain that:
- there is evidence of disrupted biology at cell membrane level
- there is evidence of abnormal brain metabolism
- there is evidence of widespread cerebral hypoperfusion
- there is evidence of 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 thermoregulation; frequency of micturition with nocturia; labile blood pressure; pooling of blood in the lower limbs; reduced blood volume (with orthostatic tachycardia and orthostatic hypotension. Findings of a circulating blood volume of only 75% of expected are common, and in some patients the level is only 50% of expected.)
- there is evidence of respiratory dysfunction, with reduced lung function in all parameters tested
- there is evidence of neuroendocrine dysfunction (notably HPA axis dysfunction)
- there is evidence of recovery rates for oxygen saturation that are 60% lower than those in normal controls
- there is evidence of delayed recovery of muscles after exercise. (Affecting all muscles including the heart.)
- there is evidence of a sensitive marker of muscle inflammation
- there is evidence that the size of the adrenal glands is reduced by 50%, with reduced cortisol levels
- there is evidence of at least 35 abnormal genes, (these are acquired genetic changes, not hereditary), specifically those that are important in metabolism; there are more abnormal genes in 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 (2006, [Online])

(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

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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 (Hyde 2007, [Online]) (Hooper et al. 2001, [Online]) (Cheney 2007, [video recording]) (Ramsay 1986, [Online])

- Myalgic Encephalomyelitis affects every cell in the body. For more information see the General articles and research overviews section. See also articles by: Dr. Elizabeth Dowsett and Byron Hyde MD.

Is there a legitimate scientific debate about whether or not M.E. is a ‘real’ medical condition?
Despite popular opinion, 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.

- For more information see: Who benefits from ‘CFS’ and ’ME/CFS’?, Smoke and Mirrors and Putting research and articles into context

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

Myalgic Encephalomyelitis does have some limited similarities – to varying degrees – to illnesses such as multiple sclerosis, Lupus, post-polio syndrome, Gulf War Syndrome and chronic Lyme disease, and others. But this does not mean that they represent the same etiological or pathobiological process. They do not. M.E. is a distinct neurological illness with a distinct; onset, symptoms, aetiology, pathology, response to treatment, long and short term prognosis – and World Health Organization classification (G.93.3) (Hyde 2006, [Online]) (Hyde 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online])

- See M.E. and other illnesses for more information. See also the new paper: M.E. vs MS: Similarities and differences

How well is research into Myalgic Encephalomyelitis research funded by government?
Governments around the world are currently spending $0 a year on M.E. research. Considering the brutal severity of the illness, the vast numbers of patients involved, this is a worldwide disgrace.

- See Research and Articles in Context for more information about research into M.E. and the challenges involved. See the Donations page to make a donation towards M.E. research and advocacy.

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

However, despite the misleading claims to the contrary made by various vested interest groups, no evidence exists which shows that CBT and 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 positive 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 routinely being prescribed these treatments on what amounts to a ‘random’ basis medically.

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. Permanent damage may be caused, as well as disease progression. 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 severe and either long-term or permanent; thus some patients are still dealing with the effects of inappropriate advice to exercise five or ten or more YEARS afterward and for some patients this damage is permanent. Sudden deaths have also been reported in a small percentage of M.E. patients following exercise. CBT and GET are at best useless and at worst extremely harmful for Myalgic Encephalomyelitis patients. Despite this, people with M.E. are routinely being recommended these ‘treatments’ while also being assured that they are completely safe. These interventions 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.). In some cases it is a condition of receiving medical insurance or government welfare entitlements that M.E. patients first undergo ‘rehabilitation’ such as CBT and GET programs, particularly in the UK.

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

It is also of great concern that so many M.E. patients are ONLY offered ‘treatments’ such as CBT and GET – while access to even basic appropriate medical care is withheld. Of the 25% of patients who are severely affected by the illness (and are bed-bound and housebound) around the majority have no contact with the health service at all as they are seldom able to obtain housecalls, for example (Dunn 2005, [Online]). Many sufferers are also refused the basic welfare support to which they are entitled. Thus a significant percentage of very physically ill and vulnerable M.E. patients are simply left to suffer and die at home without any medical care or welfare or social support (Hooper 2003a, [Online]).

- These brief comments on the effects of CBT and GET are taken from the more detailed paper: The effects of CBT and GET on patients with Myalgic Encephalomyelitis, see this paper for more information.
- For more information about the effects of overexertion on M.E. patients, including statements/research from some of the world’s leading M.E. experts about why overexertion is so physically harmful, see: Smoke and Mirrors. (This paper also includes links to patient accounts of the effects of overexertion on people with M.E.).
- A recent example of 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 shortly after being wrongly sectioned under the Mental Health Act. Sophia was severely ill with M.E. and bedbound but she was refused even basic medical care, and this is believed to have contributed greatly to her death. For more information on this tragic case, and entirely avoidable death, see: Inquest Implications, Civilization: Another word for barbarism and The Story of Sophia and M.E. For more information about forced exercise ‘treatments’ see the 100+ page CBT and GET Database.

It is only Myalgic Encephalomyelitis patients who are negatively affected by the bogus creation of ‘CFS’? Other patient groups misdiagnosed as CFS are also denied appropriate diagnosis and treatment and they may also routinely be subjected to inappropriate psychological interventions such as CBT and GET. There are also a variety of negative impacts on doctors and the public (and others) caused by the ‘CFS’ insurance scam. Truly the only groups which gain from the ‘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.

- For more information see: The misdiagnosis of CFS

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

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

I have evaluated over 2,500 cases. At worst, it is a nightmare of increasing disability with both physical and neurocognitive components. The worst cases have both an MS-like and an AIDS-like clinical appearance. We have lost five cases in the last six months. 80% of cases are unable to work or attend school. We admit regularly to lymphoid tissues, signifying the care needs such as multiple patients had been given a basic level of support and care made available to patients with illnesses with comparable stab.

Dr Dan Peterson found that: ‘M.E. patients experienced greater “functional severity” than the studied patients with heart disease, virtually all types of cancer, and all other chronic illnesses.’ An unrelated study compared the quality of life of people with various illnesses, including patients undergoing chemotherapy or haemodialysis, as well as those with HIV, liver transplants, coronary artery disease, and other ailments, and again found that M.E. patients scored the lowest. "In other words", said one M.E. expert in a radio interview, “this disease is actually more debilitating than just about any other medical problem in the world” (Munson 2000, p. 4).

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

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

- For more information on severe M.E. see The severity of M.E. and M.E. Fatalities and Why patients with severe M.E. are housebound and bedbound

- It should also be noted that even those patients with moderate M.E. are far more severely affected than many patients with a variety of other illnesses. Of course severe M.E. is even worse, but moderate M.E. can also cause severe symptoms and a relatively high level of disability and suffering, compared to many other illnesses.

**Recovery from Myalgic Encephalomyelitis**

Myalgic Encephalomyelitis patients who are given advice to rest in the early stages of the illness (and who avoid overexertion thereafter) have repeatedly been shown to have the most positive long-term prognosis. As M.E. expert Dr Melvin Ramsay explains; ‘The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, these patients who are given a period of enforced rest from the onset have the best prognosis. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them’ (1986, [Online]).

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

> After a variable interval, a multi-system syndrome may develop, involving permanent damage to skeletal or cardiac muscle and to other “end organs” such as the liver, pancreas, endocrine glands and lymphoid tissues, signifying the further development of a lengthy chronic, mainly neurological condition with evidence of metabolic dysfunction in the brain stem. Yet, stabilisation, albeit at a low level, can still be achieved by appropriate management and support. The death rate of 10% occurs almost entirely from end-organ damage within this group (mainly from cardiac or pancreatic failure) (2001a, [Online]).

Clearly, many people with M.E. are significantly or severely disabled. But what is so tragic about this high level of suffering is that so much of it is needless. The correct type of support (financial, medical and practical) can do much to prevent the physical, occupational and other deterioration in the quality of life for M.E. patients and can stabilise the illness (Dowsett 2002b, [Online]). Many deaths from M.E. could also have been prevented if only those patients had been given a basic level of support and care made available to patients with illnesses with comparable care needs such as multiple sclerosis and motor neurone disease.

- See: The 3 Part ME Ability and Severity Scale to measure your own illness severity over time.
• See Treating M.E. for more information on the importance of avoiding overexertion in M.E. and how to make sure your prognosis is as positive as possible. See also Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound.

• For information on adrenaline surges in M.E., and the different order in which certain bodily systems may be affected by M.E. (and by overexertion), see the Dr Cheney section in The effects of CBT and GET on patients with Myalgic Encephalomyelitis or Treating Myalgic Encephalomyelitis - Avoiding Overexertion.

Conclusion
Certain groups and individuals are benefiting enormously from this fraudulent artificial ‘CFS’ construct.

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

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

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

‘CFS’ is merely a scam invented by insurance companies motivated by profit without regard for truth or ethics. These groups are acting without any regard for the (extreme) suffering and 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.

Where do we go from here?
Sub-grouping different types of ‘CFS,’ refining the bogus ‘CFS’ definitions further or renaming ‘CFS’ with some variation on the term M.E. would achieve nothing and only create yet more confusion and mistreatment. The problem is not that ‘CFS’ patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually do have psychological illnesses. There is no such distinct disease as ‘CFS’ – that is the entire issue, and the vast majority of patients misdiagnosed with CFS do not have M.E. and so have no more right to that term than to ‘cancer’ or ‘diabetes.’ The only way forward, for the benefit of society and every patient group involved, is that:

1. The bogus disease category of ‘CFS’ must be abandoned completely. Patients with fatigue (and other symptoms) caused by a variety of different illnesses need to be diagnosed correctly with these illnesses if they are to have any chance of recovery; not given a meaningless Oxford or Fukuda ‘CFS’ misdiagnosis. Patients with M.E. need this same opportunity. Each of the patient groups involved must again be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group.

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

   The term myalgic encephalomyelitis was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO in their International Classification of Diseases (ICD), since 1969. The

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current version ICD-10 lists M.E. under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. (2006, [Online])

3. People with M.E. must immediately stop being treated as if they are mentally ill, or suffer with a behavioural illness, 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 or patients with any other illness than authentic Myalgic Encephalomyelitis. People with M.E. must also be given access to basic medical care, financial support and other appropriate services (including funding for legitimate M.E. research) on an equal level to what is available for those with comparable illnesses (eg. multiple sclerosis or Lupus). The facts about M.E. must again be taught to medical students, and included in mainstream medical journals, and so on.

- See On the Name Myalgic Encephalomyelitis for more information on the evidence for inflammation of the brain and spinal cord in M.E. and other issues surrounding the name Myalgic Encephalomyelitis.
- See also Who benefits from ‘CFS’ and ‘ME/CFS’?, Problems with the so-called “Fair name” campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename ‘CFS’ as ‘ME/CFS’ and Problems with the use of ‘ME/CFS’ by M.E. advocates.
- See also: Problems with ‘our’ M.E. (or ‘CFS’ ‘CFIDS’ or ‘ME/CFS’ etc.) advocacy groups (also available in an animated video format.)

What can you do to help?
Unlike people with HIV/AIDS, people with M.E. do not have an initial period of their illness where they are only mildly affected. M.E. is severely disabling even in the first week of illness. People with M.E. are almost all far too ill to stage huge protests, rallies and marches. Many with M.E. cannot even read enough to be able to understand what is happening, or they aren’t even aware that high quality scientific information on M.E. exists. Almost all so-called patient advocacy groups worldwide have sold patients out to the highest bidder and are now actively collaborating with our abusers. These groups are no longer advocates for patients with M.E. – indeed they are working directly AGAINST the interest of people with M.E. (These groups also do not help all those misdiagnosed with ‘CFS’ who do not have M.E.) The media has also sold-out and betrayed M.E. patients. The list goes on.

People with M.E. have only a tiny minority of the medical, scientific, legal and other potentially supporting professions – or the public – on their side. As the Committee for Justice and Recognition of Myalgic Encephalomyelitis explain:

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

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

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

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

This appalling abuse and neglect of so many severely ill people on such an industrial scale is truly inhuman and has already gone on for far too long. People with M.E. desperately need your help.

For more information:
For more information about the medical and political facts of M.E. see: What is Myalgic Encephalomyelitis? 

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.

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

This paper is merely intended to provide a brief summary of some of the most important facts of M.E. It has been created 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 see the References page.

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 developed into a complex illness. It is a syndrome of unexplained fatigue, multiple neurological and psychological symptoms, and a variety of abnormalities/characteristics unique to M.E. patients, however, this would seem to support the myth that ‘CFS’ is just a ‘watered down’ definition of M.E. and that M.E. and ‘CFS’ are virtually the same thing and share many characteristics.

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

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

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.

‘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. 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

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

‘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

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

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

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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.

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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.

[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 (IME) 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”.

“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”.

www.hfme.org
“(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”.

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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.’

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**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.’

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**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.

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**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.\textsuperscript{25}
Wessely in the USA. "modestly effective"; "neither approach is remotely curative"; "not the answer to CFS\textsuperscript{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.\textsuperscript{22}
Sharpe in the USA. "CBT is not a panacea" \textsuperscript{22}

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. \textbf{Key Message: UK
research on CBT & GET may suffer from bias. NICE should not take it findings at face value.}'

\textbf{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.

\textbf{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\textsuperscript{1} (which contains major nerve centres controlling bodily homeostasis) 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:

\textbf{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.

\textbf{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.”

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**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.’

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**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.

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**Chronic fatigue syndrome: assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise.** Jammes Y, Steinberg JG, Mambrini O, Breggeon F, Dellaux 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.’

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**CONCERNS ABOUT A COMMERCIAL CONFLICT OF INTEREST UNDERLYING THE DWP HANDBOOK ENTRY ON MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME**

(THET GIBSON PARLIAMENTARY INQUIRY) Professor Malcolm Hooper, Eileen Marshall and Margaret Williams, December 2005

www.hfme.org
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” (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.


‘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 neurophysiological, 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).

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 characterized 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'.”

“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, our 55.2% of patients who had a VO₂max of less than 20 mL/kg per minute correspond to class 3-4 on the disability scale, indicating moderate to severe impairment.

‘CFS can and does result in prolonged debilitation.

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!"

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**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.’

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**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.

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**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 wheelchair, I don't see the new clinics presenting any opportunity at all.'

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

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**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.)

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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.

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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 Vallings¹ 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, Michael C Barrett, David Woodrow, Jill Moss, Robert Fletcher, Leonard C Archard

‘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

‘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.

CBT in ME/CFS - More Information by Eileen Marshall and Margaret Williams, 23rd August 2006

In our document "ME Exists: True or False?” we drew attention to recognised abnormalities in ME/CFS, one of which being the significant loss of grey matter in the brain with irreversible loss of grey cells, especially in Brodmann's area 9, and mentioned that this may indicate major trauma to the brain.

If such trauma to the brain exists in ME/CFS, then the chance of cognitive behavioural therapy (CBT) being effective in ME/CFS is probably zero and the MRC PACE trials may be a disaster for the psychiatric lobby.
Circulating Blood Volume in Chronic Fatigue Syndrome  
David H. P. Streeten, MB, DPhil, FRCP, FACP  
David S. Bell, MD, FAAP  

‘Of the 19 patients reported here, abnormalities in blood volume were very common. The most common, found in 16 of 19 patients, was a reduction in red blood cell mass. Eleven subjects had low plasma volumes, and total circulating blood volume was subnormal in 12 of 19 subjects. In some individuals this abnormality was strikingly severe. Patient #15, for example, had an RBC mass of 12.9 mL/Kg, which is 46% of the expected normal, and a total blood volume of 35.8 mL/Kg, which represents 49.7% of the expected normal value (21). In general, blood pressure measurements were not predictive of the results of circulating blood volume measurements.’

ARE MPs ASKING THE RIGHT QUESTIONS?  
By Campaigning for Research into Myalgic Encephalomyelitis: RiME  
In May you asked the Secretary of State for Health a question about the new NHS ‘CFS/ME’ centres which are being developed in England. It would appear from that you are working from the assumption that people with ME welcome the centres. We beg to differ. Please read the enclosed information from our last two newsletters. As you will see, people (including health professionals) from Kent, Hants, Birmingham, Shrops, London and Manchester are either opposed to the centres or have serious concerns. We have received further complaints from other areas.

The pivotal issue in all of this is nomenclature. The Govt has both cleverly and deliberately fudged a neuro-immune-vascular disease (ME) with Chronic Fatigue and loosely defined CFS. I enclose information which contrasts the Canadian Criteria, which our supporters recognise, to the Oxford and Fukuda Criteria, which they don't. It would appear that some centres will be admitting using the Fukuda or a version of it.

People with ME deem these centres not only to be unhelpful, but to be working against their interests. Imprecise admittance criteria will produce skewed results which (1) might be used as a further excuse by the Govt for not researching the underlying physical causes of ME (the Govt, shamefully, has not invested a single penny in this area) (2) lead to a situation where people with ME's benefits are linked to them attending the 'mental rehab centres'.

To the news that the funding for the centres might run out; well, many with ME are saying 'hooray'!

There’s no smoke without fire! Some comments on the tendency to relapse in ME  
by Dr Elizabeth Dowsett  
‘ME commonly follows a virus infection, which, at first, appears to be trivial. However, the illness soon becomes distinguishable from other forms of post viral debility (including that associated with influenza) because of its prolonged course and tendency to relapse, making it inadvisable for sufferers to return to school, college or work without adequate convalescence. In a society which rates speed, sport and entertainment so highly, slowing down to rest will be unpopular and most young people will need some persuasion. The commonest causes of such a reverse in ME appear to be mental and physical over exertion.’

Submission To The Parliamentary Inquiry Into Progress In The Scientific Research Of M.E. By The 25% ME Group  
‘It seems we are constantly having to fight on different fronts concerning how ME sufferers are treated when it comes to the medical profession or the benefits agency’ writes Simon Lawrence in the (Winter 2005) Newsletter of the 25% Group.

The truth is that those with ME can be so ill and not get better; they can be so ill, not just for a few weeks, but for years on end, for decades even, without remit, without any relief, while psychiatric research accrues every single penny of Government funding for itself in a fruitless attempt to research and implement an inappropriate, harmful behavioural and exercise regime:

Giving GET and CBT to people with ME is like trying to prescribe treatment without first investigating the disease – madness! We need proper biomedical research to find out the cause(s) of this illness and to investigate fully what it does to the body. GET and CBT have been found to be at best unhelpful to those with ME at worse, harmful.
Sufferers are far too ill to protest, and too ill to ever undergo the so called behavioural remedies being developed in their name, but will never successfully treat anyone with real ME, as one sufferer explains:

“I have been ill in different phases for 15 years. I have worked it out for myself that you can only “exercise” within very narrow limits. It is simply not the case that you can exercise your way out of this illness. If it were that simple most people with ME who were previously very fit and active, would have long since recovered.”

For more see: http://www.25megroup.org/Campaigning/Gibson%20Parliamentry%20Inquiry/Gibson%20Inquiry.htm

ME/CFS Politics in a Nutshell (UK) by Kevin Short

‘Ever mindful of budgets, In the UK, Government Ministers have been captured by the psychologising views of the Wessely School, Insurance Industry and the DWP” and are pursuing their ‘Pathways to Work’ project - which is set to gain momentum from 2005. A situation where sufferers of a physical neuro-immunological disease (M.E.) will be routinely referred to psychiatrists as mental health patients – and subject to harmful ‘treatment’ upon pain of benefits withdrawal – is being set up. This is NOT exaggeration.

In spite of all the biomedical evidence to the contrary, these vested-interest psychologisers continuously maintain their anti-science mantra: that ‘M.E. is perpetuated by mistaken belief and sick-role behaviour’. Their well-funded lobby machine relentlessly bombards parliament and the media with disinformation - and they flood medical and trade journals with extremely low quality psychiatric ‘research’ papers. Inevitably, all of this adversely affects the views of time-pressed GPs who are simply too busy to read all the bio-medical research papers themselves.’


Even though post-exertional malaise is a hallmark feature of ME/CFS, exercise programs are often prescribed with little thought to the effect they may have on patients. As much care must be taken in prescribing appropriate exercise for ME/CFS patients as in prescribing pharmaceuticals.(5)

<table>
<thead>
<tr>
<th>Response to Exercise</th>
<th>Healthy People</th>
<th>ME/CFS Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of well-being</td>
<td>Invigorating, anti-depressant effect</td>
<td>Malaise, fatigue, worsening of symptoms*</td>
</tr>
<tr>
<td>Resting heart rate</td>
<td>Normal</td>
<td>Elevated</td>
</tr>
<tr>
<td>Heart rate at maximum workload</td>
<td>Elevated</td>
<td>Reduced heart rate</td>
</tr>
<tr>
<td>Maximum oxygen uptake</td>
<td>Elevated</td>
<td>Approximately ½ of sedentary controls</td>
</tr>
<tr>
<td>Age-predicted target heart rate</td>
<td>Can achieve it</td>
<td>Can NOT achieve it</td>
</tr>
<tr>
<td>Heart functioning</td>
<td>Increased</td>
<td>Sub-optimal</td>
</tr>
<tr>
<td>Cerebral blood flow</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>Body temperature</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>Respiration</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>Cognitive processing</td>
<td>Normal, more alert</td>
<td>Impaired</td>
</tr>
<tr>
<td>Oxygen delivery to the muscles</td>
<td>Increased</td>
<td>Reduced</td>
</tr>
<tr>
<td>Gait Kinematics</td>
<td>Normal</td>
<td>Abnormalities</td>
</tr>
<tr>
<td>Recovery period</td>
<td>Short</td>
<td>Days or weeks*</td>
</tr>
</tbody>
</table>

[*Note that recovery may be incomplete in some patients even after ‘days or weeks’ as this chart states; symptom exacerbation or disease progression may in fact persist for many months or years following exertion, or may be irreversible. The symptoms induced by exercise also bear little relation to mere ‘malaise’ or ‘fatigue.’ Unfortunately this information unscientifically mixes facts relating to both M.E. and ‘CFS.’]
Chronic Fatigue Syndrome May Be An Infectious Cardiomyopathy Of Single Or Multiple Viral Etiology by Maryann Spurgin, Ph.D.

The most acutely perceptive and pioneering work on CFS these days is happening in a quiet corner of the country, out of the CFS limelight. The work is being conducted by A. Martin Lerner, M.D., an infectious-disease specialist at Wayne State University, along with his colleagues in cardiology. The basic thesis of their well-documented research is that CFS is an infectious cardiomyopathy of single or multiple viral etiology -- a cardiomyopathy that in many cases is progressive and degenerative. According to the theory, CFS results when an initial infection with a virus, or a reactivation of a latent virus -- for example, EBV or CMV -- attacks cardiac tissue, producing exercise intolerance, the hallmark of CFS. The human cardiac myofiber becomes the site of persistent viral infection. The infection flares up when the infected person physically exerts him or herself.

In a normal subject, an ejection fraction will rise during exercise. They note that a stationary or falling ejection fraction is abnormal. Their work cites studies showing that declining ejection fractions are not seen in normal persons leading a sedentary life. Deconditioning and a sedentary lifestyle in normal subjects are not causes of decreasing or falling left ventricular ejection fractions.

80% of an AfME survey said the clinics were a good thing by Stephen Ralph

In sticking up for Professor Pinching and the "CFS/ME" "Fatigue" Clinics the correspondent cites a recent survey where 80% of attendees state that they were satisfied with the service provided to them.

And in the next breath the correspondent states... this survey was published in (no less than) InterAction - the publication of Action for ME who as we know are bank-rolled by the Department of Health who have given them hundreds of thousands of pounds in grants to set up these clinics based on the AfME/Westcare model with the sole aim of dishing out mental health treatments and graded exercise and nothing more.

So my comment would be... well they would wouldn't they! Of course they do not mention that they themselves or indeed Action for ME do not represent the whole ME community by far and they do not say if those attending these clinics accurately represent in any way shape or form those people who have the specific signs and symptoms of ICD10-G93.3 Myalgic Encephalomyelitis.

The fact is that this 80% figure of individuals do not present to these "Fatigue" Clinics with the specific signs and symptoms of G93.3 Myalgic Encephalomyelitis.

The Australasian Report on CFS compiled critiques by Margaret Williams, 2001

Compiled by Margaret Williams on 2 December 2001 from various critiques posted on Co-Cure

In 1996 Dr Michael Wooldridge, Minister for Health and Family Services, approved an application to Medicare to provide funding of $130,000 to the Royal Australasian College of Physicians (RACP) to produce Guidelines on the most clinically relevant and cost effective methods of diagnosing and treating CFS.

The first draft report was released in December 1997 and was heavily criticised. The second draft was released in June 2001 (this four year delay achieved nothing). As in the UK CMO’s report, the guidelines focused on the (psychiatric) management of symptoms, not on discovering their cause. They ignore the substantial evidence of organic disease.

‘The failure to mention any of the evidence of physiological and neuropsychological deficits in CFS is disappointing in a document sponsored by an authoritative body who would presumably wish to present an accurate and unbiased view of current medical knowledge…..The authors could hardly be unaware of the repeated findings by unaffiliated groups of autonomic dysfunction (and) immune dysfunction in CFS…. In conclusion, this document...will ensure that most persons with CFS in Australia will continue to be inadequately treated.’

‘The RACP seems to suggest that cognitive behaviour therapy (CBT) provides a clear understanding of CFS. This claim is unfounded and lacks evidence…CBT is not a specific strategy for CFS where its claimed benefit is still questionable….no long-term study has established that graded exercise programmes can significantly improve aerobic capacity in CFS…..It appears that the RACP has failed to recognise that post-exertional malaise is a valid CFS symptom. There is no evidence that patients with CFS demonstrate avoidance behaviour to physical activity as claimed……the second paragraph of this section is a mixture of imagination and half-truths and should be entirely deleted. The UK experience of graded exercise in CFS has shown that as a single intervention, graded exercise was associated with the highest negative grading.’
The Late Effects of ME by Dr Elizabeth Dowsett
Possible costing for ME support has been based on 3 times the cost of maintenance for multiple sclerosis on the supposition that ME is 3 times as common[4]. The only costs that we can be sure of are those derived from the failure of appropriate management, and of inappropriate assessments which waste vast sums of money and medical time while allowing patients to deteriorate unnecessarily.[16]
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![11,12,13]"

PACE TRIALS: The Background by K. Niven
The psychosocial model of ME is erroneous, illogical, and deeply offensive.
a.. It has caused misery and suffering to thousands of people with ME throughout Britain.
b.. It has stopped investigations into the illness, and thus hampered scientific progress towards a better understanding of the condition.
c.. It has led to children being refused home education, and sometimes even forcibly removed from homes, because their parents are suspected of making them ill (Münchhausen's Syndrome by Proxy).
d.. It has led to wide-spread derision and abuse of children and adults with ME by medical personnel.
e.. Patients have often been denied a diagnosis, care and appropriate advice. In many cases, they have been given inappropriate advice or therapies - like GET and CBT - which made them worse.

Comments on the CDC's latest 'CFS' press release

Comments about the current (worrying) state of Australian ME societies

A conflict of interests at the MRC by Stephen Ralph
As we all know here, the monies allocated by the MRC to the PACE and FINE trials have been handed to a select group of psychiatrists who themselves have and still do repeatedly claim to their own peer group audiences that "CFS/ME" is one in a group of Psychosomatic Disorders or to put it another way.... a mental illness that causes multi-functional impairment that they claim can be treated and indeed cured using CBT and Graded Exercise Therapy.

This CBT/GET combination is being handed out to patients currently labelled with the heterogeneously labelled "CFS/ME" now referred to singularly as "this illness" at a string of mental health "Fatigue" clinics. To sweeten the pill, Action for ME has played a key part in deceiving the "CFS/ME" community by selling such treatments to patients claiming that "CFS/ME" is a real and distressing illness but at all times using language that does not emphasise the belief of mental health origin as claimed by the somatoform psychiatrists whom AfME are supporting at the very heart of the PACE and FINE trials.

It seems to me that the Medical Research Council has a clear conflict of interests in all this.

M Hooper 1 EP Marshall 2 M Williams 2

Preface: On 14th January 2003 there is to be a meeting at The Royal Society of Medicine entitled “Chronic fatigue syndrome and factitious illness: interface between child psychiatric and paediatric services”.

[According to the Concise English Dictionary (Bloomsbury 2001), “FACTITIOUS” means “contrived or insincere rather than genuine; not real or natural but artificial or invented”].

It is intolerably patronising to insist that CBT and graded exercise therapy should be the way forward in “CFS/ME” on the grounds that such interventions may help patients suffering from other “physical” disorders
such as cancer to manage their situation better, whilst at the same time promoting and limiting research into “CFS/ME” to that designed to “strengthen” psychotherapy strategies rather than looking into underlying causes (as is the case in cancer).

The MRC “CFS/ME” Research Advisory Group seems not to agree that “Behavioural and rehabilitative strategies are fine as far as they go, but attention (and funding) must be focused on developing diagnostic tests and medical interventions to address the biological and physiological underpinnings of the illness” (36).

It is noted with particular regret that no-where in the MRC draft document is there any mention of the RiME petition (Research into ME): this petition carried over 16,000 signatures and it asked:

“That a panel of specialists in the fields of Neurology, Immunology, Endocrinology and other disciplines, but with the exception of Psychiatry, be established to commission research into the aetiology (underlying physical causes) of ME. That a research programme be up and running by the end of 2002”.

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**MYALGIC ENCEPHALOMYELITIS (ME) the impact on sufferers: is health policy in Scotland on the right path?** 21st March 2005

This is a Briefing Paper that has been sent out to all Scottish MSP's via the Cross Party Group

The clinical profile of ME is unique and does not mimic any other illness.

- Post-exertional malaise is a key defining feature.
- Patients experience a considerable exacerbation of symptoms which may precipitate a significant relapse, even after minor amounts of physical exertion.
- Mental activity can also exacerbate symptoms.

The sole source of evidence which would support behavioural interventions is research studies aiming to address the needs of patients with unexplained chronic fatigue, not ME.

The evidence for GET in respect of ME is disputed. (Appendix 3)

- In one survey of severely affected patients, 8 out of 10 reported that their illness had been made worse by graded exercise.
- Some of these patients were not severely affected before graded exercise therapy. “no other treatment (sic) – pharmacological or non-pharmacological – received such negative feedback in patient surveys” (Dept. of Health, 2002, p47)
- Biomedical research evidence supports the inappropriateness, and at worst harmfulness, of graded exercise to patients with ME.
- It is unacceptable that CBT may be applied in ways which encourage ME sufferers to believe that their illness does not have a biomedical basis.
- Duty of care is called into question if behavioural interventions are the only approaches offered to ME sufferers.

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‘Using this method, although there was significantly less vagal power in the sitting versus the standing postures for both groups, the overall vagal power was significantly lower (p < 0.034) in the CFS group versus healthy controls. Vagal power was also significantly lower (p < 0.01 to p < 0.05) at all breathing rates in both postures except while standing and breathing at 18 breaths/min.

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**Exercise responsive genes measured in peripheral blood of women with Chronic Fatigue Syndrome and matched control subjects.** Whistler T, Jones JF, Unger ER, Vernon SD. Journal: BMC Physiol. 2005 Mar 24;5(1):5 PMID: 15790422

‘Exercise-responsive genes differed between CFS cases and controls. These were in genes classified in chromatin and nucleosome assembly, cytoplasmic vesicles, membrane transport, and G protein-coupled receptor ontologies. Differences in ion transport activity/ion channel activity were evident at baseline and were exaggerated after exercise as evidenced by greater numbers of differentially genes in these molecular functions.’
Notes on the involvement of Wessely et al with the Insurance Industry and how they deal with ME/CFS claims 2003, Stephen Ralph

The insurance companies known to be involved in ME/CFS claims include, in addition to UNUM, Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life and Permanent Insurance, and as Re-insurers, the massive Swiss Re (not the same as Swiss Life). Swiss Re are currently building a huge circular eyesore in London which has been dubbed the “gherkin”. These insurance companies all seem to be involved in RE-INSURANCE; for example, Norwich Union uses Swiss Re and psychiatrist Peter White is one of the Chief Medical Officers for Swiss Re. Their other “CFS experts” are Michael Sharpe and Simon Wessely, and they also use psychiatrist Anthony Cleare (a frequent co-author with Wessely who works in the same department) for the insurers. There seem to be two ways in which claims are underwritten between insurers and re-insurers: either the insurers agree to pay claims up to a pre-determined cut-off limit, after which the re-insurer becomes liable, or else the insurer and the re-insurer agree from the outset to share the costs of a claim. This means that there is little hope of an ME claim succeeding, because both the insurers and the re-insurers all use the Wessely School psychiatrists to inter-refer claimants with ME/CFS. Given that insurers can refuse to pay out on claims until the claimant with ME/CFS has undergone a “rehabilitation” programme arranged by the insurer, this must surely result in a major conflict of interests because Peter White, Michael Sharpe and Wessely’s assistant Trudie Chalder (a former mental nurse who obtained a PhD and who seems often to be used as a grant front by Wessely) are the beneficiaries of the MRC’s latest £2.6 million grant to “strengthen” the very weak evidence that cognitive behavioural therapy (CBT or “brain-washing”) and forced “rehabilitation programmes” (graded exercise therapy or GET) actually work for those with ME/CFS, but the clear evidence is that they do not, and are in fact harmful.

THE UNDESERVING ILL - A WARNING - by John Sayer

It is my belief that the current - almost frenzied - campaign to psychologise M.E. and similar conditions is part of this propaganda and represents a dress rehearsal for the wider application of the psychosocial classification of a new "underclass" of "the undeserving ill", stripped of some of the very rights the Second World War was supposedly fought for by the Allies.

Outrageous job description for ME/CFS nurse therapist by John Sayer

These job descriptions relate to a philosophy - ALREADY IN PLACE - of subjecting "CFS" sufferers to psychotherapy designed to "prove" to them that they are simply perpetuating their own illness through aberrant belief systems.

At the risk of sounding patronising, it is time to stop considering columnists like Victor Lewis-Smith, Julie Burchill and Stacia Briggs as some kind of harmless and irrelevant joke. They are part of the propaganda machine (whether they intend to be or not) that props up this tyranny.

THE TRAVESTY OF SO-CALLED "M.E. TREATMENT" by John Sayer

Science or Psychology? Margaret Williams, 29th March 2005

“One interesting correlate of this study was the finding that the complement pathway showed significant differences between (ME)CFS and control subjects after exercise. This has been reported previously by Sorensen et al (J Clin Immunol 2003;112:397-403). Complement activation was identified as an ontology that was significantly different between (ME)CFS and control subjects after exercise”.

Why does the UK ME/ICD-CFS community have to rely on Dr Derek Enlander from the US to write to Prime Minister Blair and inform him that: “Over the past several years there is a tragedy in the manner in which the NHS and British politicians treat ME/CFS. Under your watch, millions of pounds have been misspent supporting ill-founded psychiatric notions of this disease. The cognitive behavioural programme that your government has funded is inherently flawed, in fact does harm. There is NO evidence of treatment efficacy in behaviour modification or paced therapy in this disease.
It's been almost 20 years since I was first diagnosed with ME. The controversies surrounding causes and management of ME have raged through the decades but one fact remains constant: I took a virus in 1987 and I have never had a day's full health since then. My health appears to be permanently damaged. Ditto hundreds of thousands of sufferers.

I want to express my concerns over the widely touted dictate that "Total and/or Prolonged Rest is counter-productive in ME." Even some of the moderates, who are firmly in the "ME is a serious physical illness" camp, can advocate this position. The "No Total Rest" (NTR) approach simply does not apply to my experience of severe ME.

The FINE Trial — thanks a £million? MERGE

Heralded as offering a "promising new treatment" for people with severe ME, the FINE (Fatigue Intervention by Nurses Evaluation) Trial is presently recruiting staff and will report its conclusions in 2008 or even later. Costing £1,147,000, the trial is funded by the UK's Medical Research Council with a grant to Dr Alison Wearden, a psychologist based in the Department of Psychology, University of Manchester, and colleagues in Liverpool (Department of Psychiatry) and Manchester (Department of Psychology). In the preliminary supporting documentation, the FINE Trial is described as a "randomised controlled trial of nurse-led, self-help treatment for patients in primary care... Referred patients will be randomly allocated to one of three treatment groups: (a) nurse-led self-help, (b) supportive listening or (c) GP treatment as usual." Patients will be visited in their own homes, and before "treatment" commences qualitative interviews will be conducted to explore "patient views on illness causation, beliefs about chronic fatigue, expectations of intervention, and previous experience of treatment and doctor-patient relationships". At the same time, the patients' GPs will be asked about their experiences of and attitudes towards patients with ME. After 20 weeks of "treatment", patients will be assessed for a variety of outcomes, and again after one year.

What is the "promising new treatment" on offer to the severely-ill patients? Called "nurse-led self-help" or "pragmatic rehabilitation", the approach "is designed to increase activity and challenge dysfunctional illness beliefs" (Powell et al, 1999), and includes elements of the cognitive behavioural and graded exercise therapy championed by those psychiatrists and psychologists who promote the "biopsychosocial" model of ME. The basis of this model is that "once an illness has started, its expression is affected by beliefs, coping styles, and behaviours, while consequential physiological and psychological effects act in some ways to maintain and/or modify the disease process" (CMO Report 2002). Pragmatic rehabilitation, we are told, will help patients to understand their symptoms and, jointly with the nurse, agree a programme of rehabilitation. In support of its usefulness for the most severely ill patients, a single report in the scientific literature (Powell et al, 1999) describes two wheelchair-bound patients who had dramatic improvements in health following the pragmatic rehabilitation regimen now being rolled out to larger groups of patients as a full-scale MRC-funded trial. (Two other seemingly relevant reports in the scientific literature are, in fact, small pilot studies that refer to inpatient treatments within psychiatric wards, vis, Chalder et al 1996 and Essame et al 1998.)

This treatment is not new and hardly promising on the basis of two case reports. But will some people benefit and report improvement of a sort? Well, probably — given that the quality of life of us all (well or unwell) can be improved by changing some of our beliefs and coping behaviour, and increasing our activity levels. But as the authors of the new Canadian definition of CFS/ME make clear, the question is whether such treatments (generally recognised not to be a cure for patients' physical illnesses or suitable for everyone with ME) add anything to what is available in the general medical setting, and hence whether the taxpayer-spend of £1,147,000 (including £411,000 in NHS costs, very useful for oiling the wheels of academic departments) is value for money. And furthermore, there are considerable doubts about whether the trial will address the central problem of ME.

For instance, will each severely-ill person on the FINE trial be given a comprehensive medical assessment to identify somatic (physical) symptoms and signs? Autonomic disturbances, seizures, frank muscle weakness, neuroendocrine disturbances (like sweating episodes), recurrent flu-like symptoms — will they be recorded over the 70 weeks? Symptoms like musculoskeletal pain, neurocognitive problems and sleep dysfunction — will they be comprehensively assessed? Will patients receive treatment for any of these? Or will these signs and symptoms of ME be ignored while the patients' beliefs are explored by nurses steeped in the biopsychosocial culture of their paymasters?
In vivo magnetic resonance spectroscopy in chronic fatigue syndrome. Chaudhuri A, Behan

‘Research data on magnetic resonance spectroscopy (MRS) of muscles and brain in CFS patients suggest a cellular metabolic abnormality in some cases. 31P MRS of skeletal muscles in a subset of patients indicate early intracellular acidosis in the exercising muscles. 1H MRS of the regional brain areas in CFS have shown increased peaks of choline derived from the cell membrane phospholipids. Cell membrane oxidative stress may offer a common explanation for the observed MRS changes in the muscles and brain of CFS patients and this may have important therapeutic implications. As a research tool, MRS may be used as an objective outcome measure in the intervention studies. In addition, regional brain 1H MRS has the potential for wider use to substantiate a clinical diagnosis of CFS from ... unexplained chronic fatigue.’

Specific oxidative alterations in vastus lateralis muscle of patients with the diagnosis of chronic fatigue syndrome Stefania Fulle (a), Patrizia Mecocci (b), Giorgio Fano (c), Iacopo Vecchiet (d), Alba Vecchini (e), Delia Racciotti (d), Antonio Cherubini (b), Eligio Pizzigallo (d), Leonardo Vecchiet (c), Umberto Senin (b) and M. Flint Beal (f).

From these results we hypothesize that in CFS there is oxidative stress in muscle, which results in an increase in antioxidant defenses. Furthermore, in muscle membranes, fluidity and fatty acid composition are significantly different in specimens from CFS patients as compared to controls and to patients suffering from fibromyalgia.

These data support an organic origin of CFS, in which muscle suffers oxidative damage.

Demonstration of delayed recovery from fatiguing exercise in chronic fatigue syndrome.

‘The authors attempted to confirm the consistent report by patients with the CFS of delay in recovery of peripheral muscle function after exercise. They tested the quadriceps muscle group of 10 patients and 10 controls. Recovery was prolonged in the patient group, with a significant difference between the two groups after exercise and after 24 hours. These findings support the clinical complaint of delayed recovery after exercise in patients with CFS.’

Concerns Regarding Exercise

Despite deep divisions within the ‘CFS/ME Working Group’ regarding graded exercise, the published report to the Chief Medical Officer endorsed this approach as a strategy “potentially beneficial in modifying the illness”.¹ The Cross Party Group on ME has serious concerns regarding this recommendation, and the way in which it has been interpreted. CBT can be a helpful management technique, as acknowledged in other illnesses e.g. cancer, but there are concerns that, in relation to M.E., it has come to mean motivating people to participate in ‘Graded Exercise type’ programmes. Also, CBT does seem, uniquely for M.E./CFS, to be being suggested as a ‘treatment’ and regarded as sufficient in itself, rather than an accessory to specific treatment of the illness and specific symptoms.

Time to put the exercise cure to rest? by 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 1. And, on follow up over decades (rather than weeks or months), the average person so disabled is found to be functioning (as a student, employee or parent for example) dangerously near their [activity] limits. 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.

Issues related to severe ME and the involvement of the UK Psychiatric lobby. By Greg Crowhurst, September 3rd 2005
The psychiatric lobby has been awarded £8.5 million from the Government and £2 million from the Medical Research Council (MRC) to implement the PACE trials and to set up 12 centres across the country”, where, according to one job description (2005): “severely disabled, fatigued patients and relatives (will be required ) to change perpetuating illness behaviour and perform a self-managed activity programme, regulate disturbed sleep patterns and modify predisposing personality style.” [16].

The number of patients who actually benefit from CBT and GET (Graded Exercise Therapy) in trials, is less than 10% and a large number of patients get significantly worse [21]. If anyone benefited from one of these trials they probably had some form of Chronic fatigue, but they did not have ME [22].

CFS severity is related to reduced stroke volume and diminished blood pressure responses to mental stress
Arnold Peckerman, John J. LaManca, Sharon L. Smith, and Benjamin H. Natelson; NJ CFS Research Center, University of Medicine and Dentistry of New Jersey

‘an observation was made that in patients with CFS, a lower stroke volume was highly predictive (r = -.72, p < .001) of illness severity. When divided into severe (N = 11) and less-than-severe (N = 10) groups, the severe CFS patients were found to have a lower stroke volume and cardiac output (p < .05) relative to a more moderate CFS group across three different postures.’

‘These findings suggest the possibility of a low flow circulatory state in the most severe cases of CFS. In patients with a less severe form of CFS, a diminished blood pressure response to a cognitive-behavioral (speech presentation), but not to an aversive-sensory (the cold pressor test) stressor may indicate a defect in the higher cortical modulation of cardiovascular autonomic control. In this latter group, situations may arise where a demand for blood flow to the brain may exceed the supply with a possibility of ischemia and a decrement of function.’

[Note that the so-called 'severe' patients in this study are in reality only mildly or possibly moderately ill]

Is Graded Exercise Safe for People with M.E.?

It is in relation to the endorsement of exercise that the urgent need to subgroup patients appropriately is most pressing. All interventions offered to any patient population should be as safe as possible. Lack of understanding of aetiology or cause does not mean that safety cannot be considered. The ethics of this in the case of ME/CFS are particularly relevant given the wealth of research findings which raise substantial questions about the safe prescription of exercise. Given the acceptance that the diagnosis of CFS currently encompasses a heterogeneous population, there appears to be a considerable lack of effort within clinical practice and at health policy level to take account of research indicating that the health of some patients is adversely affected by exercise.

The widespread promotion of graded exercise - and cognitive behavioural therapy aimed at increasing activity levels - has resulted in these behavioural interventions being prescribed in good faith by General Practitioners and other clinicians. However, the extent to which practitioners have knowledge of the internationally reported contra-indications for some sufferers within the ‘chronic fatigue syndrome’ banner is questionable. There has been virtually no attempt to subgroup those being referred to local services for these interventions. GPs have neither been provided with guidance as to which ‘CFS’ patients are likely to benefit from exercise, nor been advised on the need to investigate for the presence of physiological factors which would contra-indicate advising a patient to exercise.

Suggested urgent action
- GPs and other medical personnel should be supplied with the diagnostic and treatment protocol for ME/strictly defined CFS which is now available. [1]
- Every possible precaution must be taken to ensure that all medical services proposed for patients currently subsumed under the heterogeneous banner of chronic fatigue syndrome, including behavioural interventions, are safe. This would include provision of advice on contra-indications.
- Careful analysis and due consideration should be given to the findings of patient surveys and the numerous research studies which have indicated physiological abnormalities implying abnormal response to exercise, including studies suggesting that the condition of some patients is made considerably worse by exercise.

PSYCHIATRY AND PERFIDY by Gurli Bagnall, July, 2004
"Academic psychiatry has all but lost contact with the population it is supposed to serve. Criticism is, if not actively discouraged, then politely but very firmly ignored." N. McLaren, M.D. Psychiatrist, Australia, 1999

The [psychiatric] Diagnostic Manual no doubt lists a condition or two under "Personality Disorders" that match the behaviour, but what happens when people in positions of power, such as politicians and medical diagnosticians, fit the description? What happens to society when the same politicians and diagnosticians receive pecuniary and other rewards for manufacturing mental disorders where none exist?

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**Evaluating Blood Volume Studies - Some Thoughts** David S. Bell, MD, FAAP Published in Lyndonville News, March 2000

'I. Blood Volume Data. So far in our office we have measured the circulating blood volume in nearly fifty patients using the Chromium 51 method. It is essential that this method be employed (done in the nuclear medicine department of large University hospitals) as it is the only reliable method of assessing blood volume. There are two components of blood: the red blood cells and the plasma (fluid); everything else doesn't contribute much to the volume. The results are expressed as a function of body weight. Normal red blood cell mass should be between 23 and 28 ml/Kg, and the plasma volume should be between 40 and 52 ml/Kg. The total circulating blood volume is the sum of the two parts, and should lie between 60 and 80 ml/K.

Overall, about eighty percent of our patients with CFS have had either a low red blood cell mass, plasma volume, or both. Some patients have been extremely low, less than 50% of normal blood volume. To put this in perspective, if a healthy person were to bleed 40% of their volume out in a car accident it would likely be fatal. The loss in CFS is presumably gradual. The finding of decreased blood volume in CFS first came from Dr. David Streeten, and I am convinced it is accurate and will serve as a marker for the illness in some regard.'

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**One Doctor Speaks Out Against the Morbid Fascination with Psychiatric Morbidity with Regard to Chronic Fatigue Syndrome and Fibromyalgia** Alan Gurwitt, M.D.

Every so often there is an upsurge of debate about the place of psychological problems in regard to CFS, FM, and ME. As a psychiatrist who has been seeing patients with these illnesses since 1986, as well as following the literature closely, I have often been embarrassed by and angry at many of my colleagues who fall in line with self-declared "experts" who see somatization everywhere.

Ever since the mid-1980's, there have been "researchers" with an uncanny knack for cornering research funds because of their already-formed biases that are in synch with the biases of the funding government organizations, who declare CFS, FM, ME to have a psychological basis or, more recently and insidiously, avoiding specificity about etiology, indicate that CBT and graded exercise will do the therapeutic job, thus in part implying a major psychological causative factor.

I have noticed the following deficits in their work, their thinking, their word choices—or should I say-choice of terms, and their research methods…..

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**Can hysteria be diagnosed with confidence?** by Dr Elizabeth Dowsett [A review of the latest research]

"This comprehensive review, mainly of the work done by Professor Behan’s team in Glasgow begins with EPIDEMIOLOGY which, it is pointed out, has become a numbers game depending upon which ever ‘CFS’ definition is in vogue, and that the disease, in endemic or epidemic form, presents with a ‘flu like respiratory or gastrointestinal illness in 80% of cases’. A very thorough and detailed account is then given of symptoms, laboratory and other investigations. Despite some minor inconsistencies with previous advise, the review is especially valuable for this section and for its 89 references to world literature."

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**PROOF POSITIVE? Evidence of the deliberate creation via social constructionism of "psychosocial" illness by cult indoctrination of State agencies, and the impact of this on social and welfare policy** By Eileen Marshall and Margaret Williams, 30th August 2005

The ME community has for years urged UK Government bodies to fund research into both the epidemiology and the biomedical abnormalities that are known to exist in myalgic encephalomyelitis (ME, also listed as Chronic Fatigue Syndrome by the World Health Organisation in the International Classification of Diseases as Chronic
Fatigue Syndrome (CFS) as a disorder of the nervous system), almost always to no avail, to the extent that the ME community realised that there were powerful vested interests at stake which were known to involve a group of psychiatrists known as the “Wessely School”. Now, it seems, there is hard evidence of the reason for the Establishment's apparent resistance to acknowledge ME/CFS as an organic disorder and, as previously realised, it does indeed involve psychiatrists of the “Wessely School”.

The evidence is contained in a book entitled “Biopsychosocial Medicine: An integrated approach to understanding illness” edited by psychiatrist Peter White, Professor of Psychological Medicine at St Bartholomew’s and the London, Queen Mary School of Medicine recently published by Oxford University Press (2005).

This provides a most illuminating exposition of what had long been suspected; the list of contributors is itself equally confirmatory.

…Unless the disease itself is robustly investigated and understood -- and ultimately treated -- no amount of psychosocial 'management' will have worthwhile or lasting effects, either upon the hapless sufferer trying to cope without medical support with serious and destructive organic pathology or upon the cash-strapped and rapidly sinking NHS.

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**A measure of heart rate variability is sensitive to orthostatic challenge in women with chronic fatigue syndrome.** Yamamoto Y, LaManca JJ, Natelson BH.

‘The specificity in differentiating CFS from controls were 90% and 72%, respectively. The data suggest that a decrease in aperiodic fractal component of HRV in response to HUT can be used to differentiate patients with CFS from CON.’

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**The Montague/Hooper Paper** by Sally Montague and Professor Malcolm Hooper, 2001

Full title: CONCERNS ABOUT THE FORTHCOMING UK CHIEF MEDICAL OFFICER’S REPORT ON MYALGIC ENCEPHALOMYELITIS (ME) AND CHRONIC FATIGUE SYNDROME (CFS), NOTABLY THE INTENTION TO ADVISE CLINICIANS THAT ONLY LIMITED INVESTIGATIONS ARE NECESSARY

In our opinion, when taken in consideration of all that is already known about the biomarkers of ME/CFS, the evidence of serious pathology presented at Seattle emphasises the unacceptability of advising that such pathology should not be fully investigated. It also underlines the fallaciousness of advising that such substantial pathology can be satisfactorily treated by cognitive behavioural therapy or graded exercise; thus we believe it is imperative for people to be aware that the most influential members of the CMO’s Working Group are apparently still determined to proceed along such avenues despite all the evidence which has been put before them.

[Includes a summary of much of the medical research into ME]

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**CONCEPTS OF ACCOUNTABILITY?** by Professor Malcolm Hooper and The Hooper Team, 2001

This present document should be read in conjunction with the amended original Montague / Hooper paper

The release of the original Montague/Hooper document brought forth poignant worldwide gratitude from researchers and patients alike; it also brought forth an immediate barrage of letters which essentially amounted to a threatening campaign against the authors; these letters were written almost entirely by Dr Charles Shepherd, Medical Director of the UK ME Association and member of the CMO’s Key Group charged with preparing the forthcoming report, whose membership of HealthWatch was mentioned by Montague and Hooper in their paper. On his own written admission Dr Shepherd caused the Chairman of HealthWatch (solicitor Malcolm Brahams of Messrs David Wineman, Craven House, 121 Kingsway, London WC2B 6NX) to send official letters to Professor Hooper.

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Disturbingly, the prime authors of the UK Chief Medical Officer’s report on CFS/ME are apparently determined to equate ME with “CFS” as one single entity, which they refer to as “CFS/ME” (see below). To do so takes no account of the different interpretations of the undifferentiated term “CFS” and it is likely to perpetuate the existing confusion to the detriment of those with non-Oxford defined CFS. It is already known that the CMO’s Report on CFS/ME will recommend psychiatric management approaches: such approaches
may be appropriate when considering the Oxford definition of CFS but may be harmful when considering the international interpretation of “CFS” which more closely equates with ME.

Montague and Hooper believe that by seeking to equate one specific syndrome or subgroup with another syndrome or subgroup which does not have the same features, the CMO’s Working Group may be doing a grave disservice to both patients and medical science: they believe it is scientifically unacceptable that one name should refer to two different case definitions, each of which having different symptom profiles. Montague and Hooper are concerned at the repeated refusal by the CMO’s Key Group to acknowledge the clinical difference between ME and other forms of CFS, a difference which many believe has important implications for management and treatment outcomes, as well as for service provision.

[A solid overview of the medical and political facts surrounding M.E. and ‘CFS’ in the UK.]

**Exercise a health risk for chronic fatigue [syndrome] sufferers**

Adelaide scientists have found evidence that exercise programs commonly undertaken by patients with chronic fatigue syndrome (CFS), may actually make the condition worse.

**Medical Neurobiology of CFS & FM: May May 7-9, 1993 by Jay Goldstein**

It is widely documented that exercise is an exacerbator of CFIDS symptoms. Drs. Mena and Goldstein presented a series of SPECT scans which showed extreme hypoperfusion (reduced blood flow) in the brain following exercise. There appeared to be "holes" where blood would normally be flowing -- the degree of hypoperfusion was astonishing. Even 24 hours later, cerebral blood flow was severely reduced.

Cerebral hypoperfusion is not the only result of exercise intolerance. Drs. Lapp and Goldstein referenced irregular tidal volume rates common in PWCs. Hyperventilation and shallow breathing are frequent results of exertion. Normal controls breathe irregularly at the start of exercise, but respiration becomes regular over time. Dr. Lapp reported that PWCs breathed more regularly than controls at the outset, but during exercise their breathing was more variable. Dr. Goldstein concurred, "This phenomenon has never been described before in any population and, as of now anyway, we think that it's a diagnostic marker for CFS."

Neuroendocrine responses were often reversed or blunted in the Cheney-Lapp study. Cortisol, epinephrine, norepinephrine, DHEA levels and body temperature normally rise with exercise, but PWCs were found to have lower than expected measures of all of the above. Dr. Goldstein related this phenomenon to limbic dysfunction, as altered levels of interleukins and nitric oxide (NO) can result in altered neuroendocrine responses to exercise. Dr. Lapp and Dr. Kathy Sietsema reported that PWCs reached anaerobic threshold much sooner than predicted. Anaerobic threshold (AT) is the point at which a healthy person becomes completely fatigued and cannot exercise any longer (commonly called "hitting the wall"). In the Cheney-Lapp study, PWCs continued exercising beyond the point of AT. Dr. Cheney has hypothesized that PWCs normally perform above AT in everyday activity due to a metabolic injury, and therefore are more accustomed to performing at this level than controls.

**Tricky Heart May Cause ME/CFS Abnormal Heart Pumping After Exercise Linked to Chronic Fatigue Syndrome**

Peckerman's research team at the VA Medical Center in East Orange, N.J., used a sophisticated test to measure how well the heart pumps blood. They gave the test to 16 chronic fatigue syndrome patients, both before and after they exercised. They also tested four non-athletic volunteers. All of the patients' and volunteers' hearts pumped normally during rest. After exercise, however, 13 of the 16 chronic fatigue patients' hearts pumped less blood than they did at rest.

"Basically we are talking about heart failure," Peckerman tells WebMD. "But chronic fatigue syndrome is a progressive disease. If we were able to detect this in its early stages, it is quite possible there might be a way to treat it."

Emory University cardiologist Joseph I. Miller III, MD, says Peckerman's findings on a potential cause of chronic fatigue syndrome are very interesting. He agrees that these patients have serious heart problems. "Typically we see this in people with three-vessel heart disease."

What's happening to the hearts of people with chronic fatigue syndrome? It's too soon to tell, but Peckerman has a theory. "There is some indication that chronic fatigue syndrome is precipitated by a viral infection," he says. "Some of the viruses that have been suspected have an affinity for the heart."
**Dr Paul Cheney on heart issues**

"Now, do CFIDS patients prefer to stand up or lie down? Of course, they prefer to lie down. Do you know why? "Do you know what your cardiac output does when you stand up? It drops 30%. In all humans, without exception. So very critical to this technology is that it's the only one that could be done upright [again, four positions on the tilt table are best; standing up and laying down at a minimum]. And what they found is absolutely astonishing, truly astonishing. When [disabled CFIDS patients] stand up, [they're] on the edge of organ failure due to low cardiac output."

The Peckerman article Dr. Cheney refers to is available free online.

"Peckerman's research team at the VA Medical Center in East Orange, N.J., used a sophisticated test to measure how well the heart pumps blood. They gave the test to 16 chronic fatigue syndrome patients, both before and after they exercised. They also tested four non-athletic volunteers. All of the patients' and volunteers' hearts' pumped normally during rest. After exercise, however, 13 of the 16 chronic fatigue [syndrome] patients' hearts pumped less blood than they did at rest.

"Basically we are talking about heart failure," Peckerman tells WebMD. "But chronic fatigue syndrome is a progressive disease. If we were able to detect this in its early stages, it is quite possible there might be a way to treat it."

Simpson feels impaired blood flow offers a unifying thesis that can explain many of these distinct symptoms. He vividly recalls the unique response to exercise of a patient referred to him. "Two scans were done [SPECT scans] - - pre and post exercise. While the pre-exercise scan showed reduced cerebral blood flow, this was much worse in the post-exercise scan. At that time, the effects of physical activity on red cell shape had not been reported. This shows the extent of ignoring blood rheology factors as determinants of blood flow."

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**What is it About Psychiatry?** By Gurli Bagnall, 12 July 2005.

"[Psychiatry] is a field where fads and fancies flourish. Hardly a year passes without some new claim, [But]The early promises of each of these discoveries are uniformly unfulfilled." (US) Joint Commission on Mental Illness and Mental Health, 1961

What is it was about the medical profession and psychiatry in particular, that attracts the sort of person who will deliberately put a seriously ill child into a swimming pool and stand watching as he drowns. The expert who knew best, who would brook no argument, and who insisted the child's weakness would disappear once he ran out of breath, was wrong. Had the boy's fully clothed mother not jumped in to save him, he would have drowned.

[Response to Wessely on Co-cure] I would like to thank Professor Simon Wessely for his interest in my piece entitled "What is it About Psychiatry?". It is heart warming to note that, as Director of King's Centre for Military Health Research, he is taking such a keen interest in children with ME.

However, I feel I must point out that the title he gave his response ("Libelling Paediatricians"), is misleading. According to the Collins Concise Dictionary, libel means "the publication of defamatory matter" and it can only be defamatory if it is not true.

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**09-08-2004 In Dr. Lapp's words:**

This Cochrane review study is a sore subject! I obtained a copy of the entire review, and it is just horrible. The author examined 9 studies, accepted only 5, and none were from the USA. Here are some of the problems: 1. Fatigue was the main outcome measured; depression and quality of life were secondary outcome measurements. 2. Fukuda international criteria for Chronic Fatigue Syndrome (CFS) were used in only two studies, and it appears that the subjects were not terribly ill. 3. In two of the studies (Fulcher and Appleby), 80-92% of subjects were working at the time of the study; in Powell's study 35% were working. The others did not report. Obviously this was not a very sick cohort. 4. Of the 5 studies, the Appleby study was the only one with a rigorous exercise plan (70-75% of aerobic capacity for 30 minutes). This study did NOT show any improvement in subjects, and had the highest dropout rate. The 4 other studies used a low level of exercise (40% of aerobic capacity). 5. The so-called 'experts' [plural] that were listed were Dr. Peter White [only], whom I believe works closely with Wessely and...
Sharpe. Read biased. 6. Even though the authors concluded "patients with CFS who are similar to those in the
trials should be offered exercise therapy," the press did not make it clear that these CFS patients were rather high
functioning, and that most CFS patients could not tolerate such exercise. 7. The authors also concluded from this
same cohort that "exercise therapy may not worsen outcomes on average." This is very misleading since it is part
of the Fukuda definition that exercise causes post-exertional malaise, and all Persons with Chronic Fatigue
Syndrome (PWCs) may trigger prolonged relapses if they overexert. Sadly, this Cochrane review study once again
sends the incorrect message to primary physicians -- that they should exercise all PWCs and not worry about post-
exertional sequelae.

Charles W. Lapp, M.D. HUNTER-HOPKINS CENTER, P.A.

Exercise responsive genes measured in peripheral blood of women with Chronic Fatigue Syndrome and
24;5(1):5 PMID: 15790422

'Exercise-responsive genes differed between CFS cases and controls. These were in genes classified in chromatin
and nucleosome assembly, cytoplasmic vesicles, membrane transport, and G protein-coupled receptor ontologies.
Differences in ion transport activity/ion channel activity were evident at baseline and were exaggerated after
exercise as evidenced by greater numbers of differentially genes in these molecular functions. CONCLUSIONS:
These results highlight the potential use of an exercise challenge combined with microarray gene expression
analysis in identifying gene ontologies associated with CFS.

Paradoxical Proliferation of Professorial Psychiatry? by Margaret Williams, 24th October 2004

White’s assertion that “Research about its cause has been hampered by the absence of a biological marker” causes
a sharp intake of breath, as the medical, scientific and lay communities all know that whilst several biomarkers
already exist, in the UK, the continued absence of a definitive biomarker is due to the absolute refusal of
Government and government-funded bodies such as the MRC (who have been overly-influenced by psychiatrists
of the “Wessely School”) to fund any research that would reveal such biomarkers, yet sums of £11.1m are made
available to these same psychiatrists who have vested interests in claiming “CFS/ME” as a psychosocial disorder.

It is noted that having had his vested interests publicly exposed (see “Notes on the involvement of Wessely et al
with the Insurance Industry and how they deal with ME/CFS claims”, particularly Appendix I that addresses the
role of Peter Denton White as Chief Medical Officer for Swiss Re, which can be found at
http://www.meactionuk.org.uk/Notes_on_the_Insurance_issue_in_ME.htm). White does now declare his own
competing interests as being “consultancy work with the Department for Work and Pensions -- formerly the
Department of Social Security -- and with the re-insurance company Swiss Re”. People may draw their own
conclusions about such competing interests.

Transparency in Government? by Eileen Marshall and Margaret Williams, 17th October 2004

Given the much-publicised emphasis on the need for “transparency” within all Government departments, one
again has to ask how it can be acceptable for a “policy-maker” at the head of a Government Department clearly to
have had such close involvement with an insurance company like UNUM whilst he was advising Government
and formulating policy, given that (1) UNUM has been so publicly discredited for malpractice over legitimate
claims made by those with ME/CFS (as well as other incapacitating disorders), and (2) the Court-documented
aims of UNUM diametrically conflict with the needs of the sick and disabled whom the same Government
department is charged with supporting.

Vilified but Vindicated? Malcolm Hooper Eileen Marshall and Margaret Williams 29th April 2005

ME/ICD-CFS sufferers have for many years been unjustly subjected to assertions that they suffer not from an
organic condition but from either depression or from somatisation disorder, both of these being primary
psychiatric disorders. Such assertions have been promulgated mainly by adherents of the “Wessely School”, so-
named after its main protagonist Professor Simon Wessely from Guy’s, King’s and St Thomas’ School of
Medicine and The Institute of Psychiatry in London.
However, a newly published 30 page review by Professor Leonard Jason et al from DePaul University, Chicago, exposes the lack of evidence for such assertions and makes it imperative that the currently advocated management regime propounded by Wessely et al that is supported by the Medical Research Council (MRC) and funded by Government be held to rigorous scrutiny, since this regime avoids the cardinal issues surrounding ME/ICD-CFS and leaves many very sick people with no hope of correct treatment or support.

It has been said that for democracy to work, an intelligent electorate is essential. Similarly, we would suggest that for ME activism to work, an informed and committed community is essential. It must surely be inescapable to most people in the UK ME community that it is singularly ill-advised to rely on either of the major adult ME charities to over-turn the status quo of psychiatric domination. Although we can, and do, supply the tools, it is up to individual members of the ME community to make effective use of those tools by insisting on dynamic action by Members of Parliament. We understand that one large ME support group in the UK actively denies its members knowledge of our articles. We submit that the deliberate suppression of publicly available information is not democracy but dictatorship and that such dictatorship can best be overcome by papers such as this latest one from Jason et al, to whom immeasurable gratitude is due.


‘The elevated RNase L group had a lower peak VO2 and duration than the normal group, but a higher KPS. The results suggest that both exercise testing and the RNase L biomarker have potential to aid in the diagnosis of CFS.’

Vade MEcum Eileen Marshall and Margaret Williams, 28th June 2005

Two of the biggest problems currently besetting those with Myalgic Encephalomyelitis (ME) are (i) how to ensure that a physician accurately records the diverse and fluctuating symptomatology without dismissing such symptomatology as somatoform disorder and (ii) how to ensure that s/he understands that ME is not identical to “CFS/ME” as portrayed by psychiatrists of the “Wessely School”, whose papers purporting to address ME (under the umbrella of “CFS”) currently flood the literature but which bear little if any relationship to authentic ME.

Although they claim otherwise, “Wessely School” psychiatrists who advise Government and the medical insurance industry are not talking about authentic ME as listed in the WHO International Classification of Diseases (also listed as CFS, which is why it is sometimes referred to as ME/ICD-CFS) and as described by the late Dr Melvin Ramsay, but about chronic, medically unexplained tiredness that they unhelpfully refer to as “CFS/ME” and attribute to “aberrant illness belief”.

As Hyde noted in 1992: “This failure to return to the literature haunts the very basis of their definitions” (The Clinical and Scientific Basis of ME/CFS. ed: BM Hyde; The Nightingale Press, Ottawa, Canada 1992), because “Wessely School” psychiatrists glibly claim that the features documented in the medical literature about early outbreaks of ME have altered and are no longer seen. This is untrue: what seems to be true is that the psychiatric lobby fails to look for such features or to include people with such symptomatology in their studies.

Respiratory symptoms and lung function testing in Chronic Fatigue Syndrome (CFS) patients P. De Becker, I. Campine, E. Van Steenberge, M. Noppen, A. Leysl, K. De Meirleir

‘CFS patients show a significant decrease in VC, possibly due to a significant increase of RV. The incidence of bronchial hyper-responsiveness in this group is also remarkably high. These observations can, at least partially, explain the respiratory symptoms in these patients.’

Evidence Based Psychiatry Eileen Marshall and Margaret Williams, 12th June 2005

Apart from identified gene abnormalities, other researchers have found abnormal immune activity in the pathology of exercise intolerance in ME/ICD-CFS that is consistent with a channelopathy involving oxidative stress and nitric oxide-related toxicity (Exercise capacity and immune function in male and female patients with chronic fatigue syndrome. Snell CR et al. In Vivo 2005:19(2):387-390).
Consistent with the above findings, Jammes et al have shown that in the ME/ICD-CFS patients studied, exercise gives rise to abnormally increased oxidative stress, resulting in patients being quite unable to respond physiologically, which could well account for the reduction in muscle power after exercise as reported by patients and as demonstrated by Paul et al (European Journal of Neurology 1999:6:63-69). The observed changes in markers of exercise induced oxidative stress are considered by the authors to be of real significance, and the paper confirms previous studies that point to positive correlations between muscle symptoms and measures of oxidative stress (Chronic fatigue syndrome: assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise. Jammes Y et al. Journal of Internal Medicine 2005: 257: 299-310).

Clearly, those with ME/ICD-CFS are physically, not mentally, sick: it may be helpful to highlight once again what Professor Nancy Klimas from the University of Miami said in her AACFS in-coming Presidential address: “Our patients are terribly ill, misunderstood, and suffer at the hands of a poorly informed medical establishment and society” (Co-Cure 21st March 2005: http://www.co-cure.org).

Questions for the MRC  Eileen Marshall and Margaret Williams, 18th June 2005

It cannot be repeated often enough that what Wessely School psychiatrists choose to call “CFS/ME” is not ME/ICD-CFS (a term used because ME is also known in the ICD as “CFS”) and should not therefore be described in their studies and results as pertaining to ME/ICD-CFS. To do so is both a failure of their professional responsibilities to patients and a corruption of the scientific process.

The Story of Sophia and M.E.  (from the Invest in M.E. website)

This is the heartbreaking story of Sophia, who through medical maltreatment and neglect, died of M.E. in 2005. This story illustrates all too tragically that M.E. is a serious neurological illness which is too often dismissed out of hand by doctors; sometimes with devastating consequences. An excerpt:

In July the professionals returned - as promised by the psychiatrist. The police ‘smashed the door down’ and Sophia was forcibly removed and taken to a locked room within a 'secure' ward of the mental hospital. Despite the fact that she was bed-bound, she did not have even basic nursing care; her temperature, pulse and blood pressure (which had been 80/60), were never taken, her bed was never made, she was never washed, her pressure areas were never attended to and her room and bathroom were never cleaned. The nurse asked me to cook for her as the processed hospital food made her more ill. Sophia also had to deal with many nurses constantly going into her room and talking to her.

The psychiatrist made it quite clear to Sophia’s solicitor that he would not release Sophia. However, two weeks later, after a tribunal lasting 8 hours, she was released. It was too late; the damage had been done. Sophia relapsed, not to where she had been before, in spring 2003, but to a hell hole to which she had never been. She never recovered from their maltreatment. She never stood a chance.

The result of the inquest into the death of Sophia Mirza (on Invest in ME)

Inquest Implications  by Eileen Marshall and Margaret Williams, 16 June 2006 [On the inquest into the death or Sophia Mirza.]

'General Medical Council’s “duties of a doctor” (2001) state that doctors must make the care of the patient their first concern and they must not ‘give or recommend to patients any investigation or treatment which (they) know is not in their best interests, nor withhold appropriate treatments’. This was acknowledged on 15th June 2006 by Dr Susan Benbow of The Royal College of Psychiatrists in the Daily Telegraph. The GMC stipulations are clear enough, so why then are sufferers from ME/CFS excluded from such protection?

There can be few people in the UK ME community who have not by now heard the results of the inquest into the tragic death from ME/CFS of 32 year-old Sophia Mirza, the beloved daughter of Criona Wilson from Brighton. Although severely sick with medically diagnosed ME/CFS, Sophia was abused by the doctors charged with her care by being wrongly sectioned under the Mental Health Act.'

Civilization: Another word for barbarism  by Gurli Bagnall 17 June, 2006 [On the inquest into the death of M.E. sufferer Sophia Mirza.]
'At one time, sick people recuperated or convalesced. Now according to a group of megalomaniacal brain-washers and self-elected "law-makers", they are expected to rehabilitate along with murderers, rapists and thieves. The law which states that a person can only be sectioned if he is a danger to himself and/or others, has been swept aside by the above mentioned self-serving monsters masquerading as doctors.

Many will dismiss this as fanciful rubbish. After all, we live in civilized societies where such things could never happen. Unfortunately, they can and they do. It happened to the recently deceased Sophia Mirza.'

**The Ean Proctor Story**

In this “care”, the sick child was forcibly thrown into a hospital swimming pool with no floating aids because psychiatrists wanted to prove that he could use his limbs and that he would be forced to do so to save himself from drowning. He could not save himself and sank to the bottom of the pool. The terrified child was also dragged out of the hospital ward and taken on a ghost train because psychiatrists were determined to prove that he could speak and they believed he would cry out in fear and panic and this would prove them right.

Another part of this “care” included keeping the boy alone in a side-ward and leaving him intentionally unattended for over seven hours at a time with no means of communication because the call bell had been deliberately disconnected.

**Ean’s Story** by Barbara Proctor, Ean’s mother

An excerpt: ‘On Monday 23rd May, two social workers arrived on our doorstep and took Ean away under a “Place of Safety Order”. We were not even allowed to go with Ean in the ambulance. Ean was to be in the joint care of Dr C, a psychiatrist, and Dr B, a paediatrician, at the local hospital.

During the whole time Ean was in care, we were allowed to see him for only half an hour a day. He was alone in a ward, could not move, could not speak, and had no way of getting help if he needed it. He had been told that he had been taken away from us because he was dying. Ean had to endure the most horrific mental torture. One day the psychiatrist told him "There is nothing wrong with you.... if you don't talk next week, you will be better off in Ballamona [the mental home]". Ean was so scared, he wet himself as he sat in his wheelchair. The Staff nurse would say to him that if he didn't speak or walk "He would grow old in his wheelchair, stay in the hospital for ever, and never go home again". One night, Rob and I found him very distressed in his wheelchair, all alone. He had wet himself, as no-one had asked him if he wanted to go to the toilet, at lunchtime... It was now 7.40 pm. Friday was the day Ean lived in dread of. This was the day the physiotherapists would take him off to the remedial pool.

Ean’s case is also mentioned in:

**To set the record straight about Ean Proctor from the Isle of Man** By Eileen Marshall and Margaret Williams, 20th July, 2005

**Inadequacy of the York (2005) Systematic Review of the CFS/ME Medical Evidence Base.**
Comment by Professor Malcolm Hooper & Horace Reid, January 2006

**Another Meadow?** by Eileen Marshall and Margaret Williams, 16th July 2005

**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)** by Margaret Williams et al. 16th January 2003

**Issues re the use of the Oxford criteria for the MRC “CFS” Trials** by Margaret Williams, 20th June 2004

The Oxford criteria select patients who "present with a principal complaint of disabling fatigue of uncertain cause" and the stated aim of the Oxford meeting “was to seek agreement amongst research workers for the reporting of future studies of patients with chronic fatigue”. This is not the case in ME/CFS, where patients experience post-exertional muscle fatigability which is not the same as “fatigue” or chronic tiredness (see JAMA, July 1990).

The Oxford criteria state "Specifically, we set out to agree on which patients should be included": given the stated aim of the Oxford criteria, this means the criteria set out to select patients with chronic fatigue, not ME, yet the MRC study purports to be studying those with “CFS/ME”.

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The Oxford criteria state: "The following guidelines were agreed. There are no clinical signs characteristic of the condition. Psychiatric disorders (including depressive illness, anxiety disorders and hyperventilation syndrome) are not necessarily reasons for exclusion".

Bearing in mind the requirement for compliance with the Oxford criteria, on what precise grounds can the MRC “CFS/ME” trials that will rely on the Oxford criteria for entry into the trials include those with ME, who may have an abundance of characteristic physical signs?

Complement activation in a model of chronic fatigue syndrome. Sorensen B, Streib JE, Strand M, Make B, Giclas PC, Fleschner M, Jones JF. Department of Pediatrics, National Jewish Medical and Research Center, Denver, CO, USA.

‘Exercise challenge induced significant increases of the complement split product C4a, but not C3a or C5a, at 6 hours after exercise only in the CFS group (P <.01), regardless of allergy status. Mean symptom scores were significantly increased after exercise through the use of a daily diary (P <.03) and a weekly diary (P <.01) for the CFS group only.’

‘Exercise challenge may be a valuable tool in the development of diagnostic criteria and tests for CFS.’

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) by Margaret Williams et al. 16th January 2003

Tactics used by psychiatrists of the "Wessely School"

In their apparent desire to suppress dissemination of research into ME which does not accord with their own narrowly-defined parameters of psychiatric illness, these psychiatrists consistently use the same tactics: it is fair to say that by virtue of the sheer volume of his published papers, Wessely himself must be considered the prime proponent.

By their repeated and therefore apparently deliberate ignoring, dismissing or trivialising of the research evidence with which they do not agree, Wessely and his own psychiatric lobby misinform and mislead readers, both medical and lay, thereby influencing and manipulating the perception of ME/CFS which their readers will acquire. Such intellectual manipulation is achieved by outright selectivity which might even amount to deception, and by biased use of the available published referenced literature on ME/CFS, a technique of which Wessely especially is master on the grand scale. By using this particular tactic, these psychiatrists fail to provide a balanced overview of the available published evidence on the state of knowledge about ME/CFS and thereby seem to be attempting to remove discourse on the nature of ME from the scientific arena, but good science thrives on open and honest scientific debate.

Margaret Williams reviews quotations from "SOMATIC MEDICINE ABUSES PSYCHIATRY - AND NEGLECTS CAUSAL RESEARCH" by Per Dalen, January 2003

UNUM Provident, Dr Michael Sharpe and Cognitive Behavioural Therapy: Information which the Medical Research Council might wish to consider. By Eileen Marshall and Margaret Williams, 12th April 2003

Given that research funds are said to be so limited (though it must not be forgotten that, quite apart from any recommendations of the MRC RAG, the sum of £2.6 million has passed its first MRC review and is well on the way to being awarded to psychiatrists Mike Sharpe (Edinburgh), Simon Wessely (King’s College, London) and Peter White (Bart’s, London) for a 4 year project looking at the use of CBT and graded exercise as effective treatment for people with ME/CFS) and particularly in view of the scathing criticism of the work of the MRC detailed in the recent Report of the House of Commons Science and Technology Select Committee (reference HC132), what is the MRC’s explanation for wishing to fund yet more psychosocial research on “CFS/ME” (an entity which does not officially exist either by definition or classification) in attempts to “strengthen” the small number of existing poor-quality studies on the alleged effectiveness of CBT in preference to funding soundly-based projects on the known biological abnormalities which underpin this disorder?
This is a question to which the MRC’s answer is over-due.

**Time for a Reality Check at the UK Department of Health?** By Margaret Williams, 3rd April 2004

From the above, it can be seen that the Department of Health and its associated official bodies are not “neutral” about ME/CFS as claimed on 31st March 2004 on behalf of Secretary of State Dr John Reid. What can be clearly seen is that either the Department of Health does not know what it is doing from one day to the next or, on no good evidence, it has allowed itself to be overly influenced by the psychiatric lobby. In my opinion, this makes their present unquestioning acceptance of the Wessely School’s expediently constructed psychiatric paradigm all the more culpable.

**Sinister Science** By Margaret Williams, 6th June 2004

On 3rd June 2004 Christine Hunter from Australia, whose daughter Alison died of severe ME aged just 19, was moved to ask where is the response of the worldwide ME community to the CDC International CFS Study Group's proposed refinement of the 1994 CFS criteria (published on 31st December 2003).

**Observations on Professor Simon Wessely’s evidence to Lord Lloyd’s Public Inquiry into Gulf War Illnesses** by Eileen Marshall and Margaret Williams, 28th August 2004

The question has to be asked --- should Wessely not be invited to explain his constant rejection of scientific biomarkers of serious physical illness (albeit too new to be as yet fully understood) and his assiduous replacement of them with his own psychiatric theories, when his theories can never be scientifically proven?

In his evidence to the Public Inquiry, Wessely’s overall objective seems to have been to reject and deflect any evidence that posed a threat to his own carefully constructed paradigm of a non-existent Gulf War Syndrome. Is it the case that his mission – or should one say his commission – has paid off handsomely?

It is perhaps worth mentioning that some time ago, Wessely apparently actually said to someone that he didn’t give a f--- about the Gulf War veterans: he had got his Chair and that was all that mattered.

**Evidence-based Policy or Policy-based Evidence?** by Professor Malcolm Hooper Eileen Marshall Margaret Williams, 20th November 2005

For example, in the American Family Physician, a peer-reviewed journal of the American Academy of Family Physicians (one of the largest groups of physicians in the US), the issue of 1st November 2005 (volume 72, no. 9) features CFS in the section Clinical Evidence Concise, this being a section that purports to provide evidence-based continuing medical education (CME) for the credits that are required to be obtained by all physicians to demonstrate their up-to-date medical knowledge; the articles in Clinical Evidence Concise purport to summarise current knowledge about a disorder and are used in best practice guidelines. In this particular issue, the topic is CFS and the authors are Steven Reid, Trudie Chalder, Anthony Cleare, Matthew Hotopf and Simon Wessely. What is so disturbing is that this is a re-run of the same authors’ paper in the BMJ of January 2000, which was a shortened version of their original article in the second issue (December 1999) of Clinical Evidence, a BMJ Publishing Group Review. For these authors to publish it once again six years later demonstrates their total refusal to pay any heed to the wealth of biomedical evidence about ME/CFS that has been published in the intervening six years and would seem to be an abuse of the scientific process as well as an abuse of those with ME/CFS. As Jill McLaughlin noted on MEActionUK@yahooogroups.com : ‘This is what is being distributed to physicians all over the country who legitimately use evidence-based medicine to treat (or in this case, shall we say, mistreat) patients. We cannot always rail at doctors when this is the information that they are receiving in mainstream, peer-reviewed medical journals’.

**Brief comments on the DWP proposed entry on “CFS/ME” (version 8 of March 2006)** by Margaret Williams, 26th March 2006

Para 1: In the “Definition”, many key symptoms and features of true ME/CFS are again omitted: since the Guidance is not limited to mild forms of the disorder (but covers the entire spectrum of severity), why have such symptoms as cardiac insufficiency, neuromuscular incoordination, respiratory dysfunction, vertigo...
/balance problems, inability to stand unsupported for more than a few moments, frequency of micturition / nocturia, pancreatic insufficiency, chest pain, parasympathetic enteropathy etc been omitted? This would seem to amount to deliberate disinformation.

Para 2: again, there is obfuscation about which disorder is being discussed. It is untrue that “most authorities consider the condition as CFS/ME”; the people who use that term are Wessely School adherents and UK Government bodies whom they have influenced. The term was coined by Wessely himself, who wrote in the BMJ: “It may seem that adopting the lay label (of ME) reinforces the perceived disability. A compromise strategy is ‘constructive labelling’: it would mean treating CFS as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer’s report of the term CFS/ME reflects such a compromise” (BMJ 2003:326:595-597). It must not be forgotten that Wessely’s version of “CFS/ME” equates with neurasthenia.

Some of the abnormalities that have been demonstrated in ME/CFS by Eileen Marshall and Margaret Williams, 31st March 2006

In view of the fact that the peer-reviewed research data supports the following organic abnormalities in ME/CFS, how can so many members of the UK medical profession still persist in the belief that ME/CFS is a behavioural disorder? It is shameful that UK Government bodies have consistently refused to fund any biomedical research into this devastating disorder.

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, 12th December 2005

174 pages.

Prepared for The Group on Scientific Research into Myalgic Encephalomyelitis (the Gibson Parliamentary Inquiry) that has been established “to assess the progress of scientific research on ME since the publication of the Chief Medical Officer’s Working Group Report into CFS/ME in 2002, (and) to increase public understanding of scientific research into ME/CFS (and) to identify research and funding requirements in establishing the cause of ME/CFS”.

This document is a compilation of illustrations taken from the published evidence-base of the organic aetiology of ME/CFS over the fifty years from 1955 to 2005.

Informal notes on the issue of funding biomedical research into ME/CFS Margaret Williams, 17th July 2006

The real stumbling block is that it is Government policy not to carry out biomedical research into ME/CFS: this is because the Government is taking advice only from the psychiatric lobby themselves. Layard & co are determined that CBT is the answer, and Wessely is on record as stating that ME is simply a "belief" that one has a disorder named ME.

Wessely was on no less than three MRC Boards, which might explain why the MRC itself classified ME/CFS as a mental disorder --- see page 32 of the Report of January 2005 from the MRC Neurosciences and Mental Health Board's Strategy and Portfolio Overview Group, which clearly states: "Mental health in this instance covers CFS/ME" (NMHB Mental Health Scoping Study Report).

Notably, Professor Pinching informed the Gibson Inquiry that he expects to implement the NICE guidelines next year: since these are not officially known, this lends credence to the widely-held belief that the NICE guidelines will merely re-echo the view already expressed and published in an "Effective Health Care" bulletin, May 2002:7: (4), a publication that was disseminated throughout the NHS and funded by NICE itself, which emphasised that CBT and GET are the treatments of choice for "CFS/ME". There is concern in the ME community that the Government and the MRC set the outcome they wish to achieve. This being so, it would be remarkable if NICE were to produce guidelines that are substantially different from its already documented view of the same issue. Should the forthcoming NICE guidelines advocate nothing but CBT and GET, this would ignore the significant body of published research and clinical knowledge that ME/CFS is not a mental health (behavioural) disorder and would make a mockery of the Government's purported commitment to improving understanding of what is a
serious, multi-system disorder that, unless addressed as a matter of urgency and treated appropriately, will continue to wield a huge potential for bankrupting the NHS.

**Influence of exhaustive treadmill exercise on cognitive functioning in chronic fatigue syndrome**

La Manca JJ; Sisto SA; De Luca J; Johnson SK; Lange G; Pareja J; Cook S; Natelson BH C.F.S.

“We conclude that after physically demanding exercise, CFS subjects demonstrated impaired cognitive processing compared with healthy individuals.”

**Notes re the evidence of Raymond Perrin PhD to the Gibson Parliamentary Inquiry into ME**

Eileen Marshall and Margaret Williams, 1st July 2006

18. Before criteria can be used to select patients for a study, they need to be defined and published in an accessible form in a medical journal. None of the various versions of the "London Criteria" has ever been published in a peer-reviewed journal.

19. Notwithstanding the above, in 2004 AfME announced that the MRC-funded PACE trials on CFS will use the "London Criteria" in addition to the Oxford criteria, and this was supported by Dr Charles Shepherd of the ME Association. Given that, by case definition, the Oxford criteria specifically exclude those with a neurological disorder (and the WHO classifies authentic ME as a neurological disorder), it must be asked what exactly is the case definition upon which the MRC trials are based, and if the necessary rigorous scientific standards are being applied in the case of ME/CFS?

**AACF disappoints** by Jill Mclaughlin

There were many presentations and discussions of the same aspects of sleep, exercise, goal setting, counseling, and CBT that we've all heard over and over. Trudy Chalder of the UK, a Wessely colleague, gave a talk on CBT. From reports I've seen, her presentation made very little scientific sense. While she apparently states that CFS is a physical rather than psychological illness, she then goes on to present CBT and exercise as the way to overcome symptoms and thus achieve normality -- which requires little more than sleep management, keeping regular hours, avoiding naps and a realistic exercise plan - even if it results in worsening of symptoms. This is absurd and contradictory and, and more to the point, harmful, to patients who are very ill. To ignore the patient's experience and tell them to ignore their symptoms - not only if they do not improve but even - especially - if they are worsened, is abusive. She further claims that patients should concentrate on overcoming symptoms rather than looking for a cause of symptoms. This presumptive, value-laden, arrogant approach is the ultimate in "blame the victim" - not only for their symptoms but their inability to overcome them.

The complexity of CBT studies, variability of the interpretation and application, their varied inclusion and exclusion criteria, the logistical difficulties in ensuring that they are properly blinded, the high drop out rates, and the subjective means used for most evaluations, raises serious doubt as to the validity of any of them.

**The dangerous dominance of Psychiatry in ME/CFS** - By Stephen Ralph

It is quite obvious to many who have taken interest in the present situation that psychiatrists are in fact the wrong tool for the job regardless of how esteemed or respected they are. Being esteemed and respected can in fact make them even more dangerous to patients if no one dares to question their fundamental beliefs. These so called respected and esteemed doctors become unstoppable which then allows them to take ME/CFS medicine up a very long blind alley. In doing this these doctors provide nothing for patients and indeed they then harm patients exploiting their unquestionable beliefs. Years will be wasted on such a situation whilst those clinicians concerned spend their time simply earning vast amounts of money handed to them by the Department of Health through the Medical Research Council through the maintenance of their feckless arrogance and their faulty belief systems.

Meanwhile the patients will gain nothing from them and will go on suffering.
Insufficient data, inappropriate conclusion an article about CBT on the BMJ Journal website

Comments by Abhijit Chaudhuri, Senior Lecturer in Clinical Neurosciences University of Glasgow

I have a few concerns regarding the design and interpretation of this published trial (1). First, the trial arms were not matched for the number of contacts with the health care professionals. Experience from larger and more carefully controlled randomised interventional trials of patients with chronic fatigue syndrome has clearly shown that short-term improvement in symptoms are directly related to the maintenance of regular contacts with the health care professionals rather than due to the therapeutic effect of the intervention itself and consequently, the improvement is not sustained once the contact is lost (2). The authors did not offer patients in their waiting list the opportunity to meet therapists regularly for five months but without having cognitive behaviour therapy (CBT). In addition, there are no follow-up data regarding patients in the intervention arm beyond five months to show that the specific treatment benefit was carried forward in the absence of regular contacts with the therapists. Taken together, one has to be extremely cautious in inferring direct benefit from CBT in the intervention arm (as opposed to short-term benefit from close contact with therapists) and such a claim would only reflect uncritical belief in the efficacy of CBT.

Second, the authors indicated that a proportion of their patients were “passive”, i.e., adolescents who spend “most time lying down and go out infrequently… most do not attend school at all” (p2, intervention). The baseline characteristics show that all participants were attending school - either full time or part time (Table 1) and yet nearly a third of patients in the intervention arm were considered to be “passive” by the authors. I am not sure if these data are compatible with their own definition of passivity (1). May I ask what were the outcome results of subgroup analysis in the so-called “active” and “passive patients?”

Third, the results (Table 2) did not show how many adolescents in each arm returned to full-time schooling, clearly a more meaningful and simpler index of response to therapy.

Fourth, it was suggested that the intervention (CBT) was effective by challenging patients’ belief that activity would aggravate symptoms (p2, “intervention” and p5,“what this study adds”). If it is true, then I am afraid the authors challenged a scientific fact because epidemiological data confirm that [symptoms] made worse by exercise is a characteristic feature of chronic fatigue syndrome (3). Encouraging activity in disabled patients is entirely different from challenging an accepted feature of the disease: e.g., when a patient with hemiparesis is encouraged to walk, the existence of weakness due to a stroke is not challenged.

Finally, the trial recruited relatively small number of patients and given a high drop-out rate (nearly 20%) of the participants in the intervention arm, there is a possibility of Type 2 error.

In conclusion, the study does not have the strength to conclude that “CBT is an effective treatment for chronic fatigue syndrome in adolescents”(1). Amendments regarding the conclusion and the rhetorical summary point of this paper are to be expected from the authors and/or the editors. Failure to do so would perpetuate the view that the BMJ has a selective bias towards research that supports a psychological view of chronic fatigue syndrome irrespective of the quality of the presented material.

CBT, peer pressure and wishful thinking Ken S Linder comments on the same article

Despite many years of trying to prove the effectiveness of CBT in the treatment of chronic pain and various other chronic illnesses, there has never been a scientific peer reviewed paper that demonstrated any statistically significant positive outcome from CBT in the actual reduction of pain or in the curing of an illness or even the reduction of physical symptoms. Yet, those dedicated to its use continue to believe that if they do the same thing again and again (CBT in a CFS patient) they will get a different result. This is known as ”Magical Thinking”.

From the Assistant Secretary of Health Dr Philip Lee, U.S. Chair of Chronic Fatigue Syndrome Co-ordinating Committee (CFSCC), 13 September 1996:

There is mounting evidence that:

a. early diagnosis and aggressive rest, particularly in the initial stage, can have a crucial influence on duration, severity and recovery;

b. each person with ME/CFS (child or adult) has to find his/her own safe limits and can not have activity, mental or physical, prescribed by others; mental activity can be every bit as detrimental as physical exertion.

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It is widely documented that exercise is an exacerbator of CFIDS symptoms. Drs. Mena and Goldstein presented a series of SPECT scans which showed extreme hypoperfusion (reduced blood flow) in the brain following exercise. There appeared to be "holes" where blood would normally be flowing -- the degree of hypoperfusion was astonishing. Even 24 hours later, cerebral blood flow was severely reduced.

Cerebral hypoperfusion is not the only result of exercise intolerance. Drs. Lapp and Goldstein referenced irregular tidal volume rates common in PWCs. Hyperventilation and shallow breathing are frequent results of exertion. Normal controls breathe irregularly at the start of exercise, but respiration becomes regular over time. Dr. Lapp reported that PWCs breathed more regularly than controls at the outset, but during exercise their breathing was more variable. Dr. Goldstein concurred, "This phenomenon has never been described before in any population and, as of now anyway, we think that it's a diagnostic marker for CFS."

Neuroendocrine responses were often reversed or blunted in the Cheney-Lapp study. Cortisol, epinephrine, norepinephrine, DHEA levels and body temperature normally rise with exercise, but PWCs were found to have lower than expected measures of all of the above. Dr. Goldstein related this phenomenon to limbic dysfunction, as altered levels of interleukins and nitric oxide (NO) can result in altered neuroendocrine responses to exercise.

Dr. Lapp and Dr. Kathy Sietsema reported that PWCs reached anaerobic threshold much sooner than predicted. Anaerobic threshold (AT) is the point at which a healthy person cannot exercise any longer (commonly called "hitting the wall"). In the Cheney-Lapp study, PWCs continued exercising beyond the point of AT. Dr. Cheney has hypothesized that PWCs normally perform above AT in everyday activity due to a metabolic injury, and therefore are more accustomed to performing at this level than controls.

Dr Darrel Ho-Yen of Scotland, (a well respected M.E. researcher and virologist) was published in the British Medical Journal in 1994:

"Patients with (ME/CFS) should be advised not to increase their activities gradually until they feel 80% of normal." (BMJ 1994:309:1515).

Dr. Dowsett believes that the polio vaccine made room for other polio-like viruses (from the family of viruses called enteroviruses) to take over. According to Dr. Dowsett's research and other work, these other viruses may even hit some parts of the brain harder than in polio, judging by the brain fatigue and research on the ME/CFS brain. So, even if people with ME/CFS don't have paralysis and get as physically weak as people who had polio, they may be even more impaired in other ways.

This has VERY IMPORTANT implications for assessment of disability and for treatment.

Important Treatment Information: Dr. Bruno says pacing, NOT cognitive behavioural therapy and NOT graded exercise, is the cornerstone of treatment for people with PPS and ME/CFS. The key message is that people with ME/CFS and PPS have demonstrated brain stem dysfunction. This explains a multitude of symptoms because the brain stem controls so many physical and mental processes. Dr. Dowsett supports this view.

As the Canadian Newsletter ‘Quest’ reports, both Dr Dowsett’s and Dr Bruno’s presentations are amazing. Dr Dowsett tells of her work throughout the years on ME/CFS and PPS and linking it up with the Post Polio Sequelae. Dr Bruno is admirable in his determination to get over to people the effects of PPS, ME/CFS. and what can be done to allow people to help themselves improve their quality of life.
It is surely regrettable that Wessely persistently fails to apply his own criteria when he is addressing the issue of ME/CFS, his studies of which having been criticised in the literature for lacking the necessary rigorous scientific scrutiny.

Unless corrective measures are taken by NICE to ensure that their final guidelines for ME/CFS are unbiased and are based on sound and reliable evidence, they will not be effective.

Your article says that in November 2005 NICE commissioned BMJ Learning to produce a series of learning modules based on its guidance. If the future module for ME/CFS were to rely solely upon the intended NICE guidelines, it will not exemplify the standards you endorse in your article.

PRESS RELEASE & GENERAL STATEMENT

By the 25% M.E. GROUP – National Support Group for Severe M.E. Sufferers.

Quote: Are a small group of vocal researchers trying to hijack vast amounts of public money? In excess of £4 million has already been spent by psychiatrists trying to prove that CBT/GET are the most appropriate forms of treatment for CFS/ME. Despite this a major review of evidence for the government described the evidence as "poor". Now a proposal to spend a further £2.6 million within the psychiatric field is being considered. This is despite the fact that ME is a multi-system/multi-organ disease, which has been formally classified by the World Health Organisation as a Neurological Disorder since 1969.

Worse still, many people with "classic" ME report that these forms of treatment are the most unhelpful and harmful to their health and often severely restrict any improvement in their condition. In a recent ME patient survey, it was found that up to 50% \(^{(1)}\) were made worse by Graded Exercise Therapy. In the same survey, 93% \(^{(1)}\) found rest and pacing of their condition much more helpful in managing their illness.

Unhelpful Counsel? MERGE's response to the CMO working report on ME/CFS.

An excerpt: "In one patient-group survey, only 7% of respondents found the therapy [CBT] ‘helpful’, compared with 26% who believed it made them ‘worse’. The remaining 67% reported ‘no change’.”

ME/CFS and the Media

Evidence from over 1,000 sufferers submitted to the Chief Medical Officer's Report on ME indicated that 67% found CBT resulted in "no change" to their condition (7% found CBT "helpful"; 26% said it made them "worse") and almost 50% reported that GET had made their condition "worse" (35% found it "helpful"; 15% reported "no change").

In fact, 50% of patients who filled in a treatment questionnaire for the Chief Medical Officer's report stated that an exercise programme had made their condition worse.

If ME/CFS were simply the result of depression, inactivity, and lack of motivation - as many of my professional colleagues still believe - then exercising your way out of it would be a perfectly logical solution. However, current research strongly points to the fact that there are genuine physiological and neuromuscular reasons why these people are unable to return to normal levels of fitness - no matter how hard they try.

A Call for Help - By Stephen Ralph (on the ‘fatigue treatment’ clinics in the UK)

We cannot let these people get away with this.

We cannot let these clinics be hijacked by the mindset of psychiatry who plan to spread their word and their beliefs through these clinics to the families of ME sufferers and the wider communities who will go to these clinics for advice as will your GPs and the media once these clinics have been set up with staff who will be educated by such adverts and the people who wrote them along with their managers who are all forcing through this mental health agenda. I think this whole situation is totally appalling.

Sharpe Editorial Comment by Stephen Ralph
The "Wessely School" have attempted to convince their peers via a worldwide network of likeminded colleagues that ME/CFS is a "disorder" that can be treated and cured by CBT and Graded Exercise - claiming that ME/CFS is predominantly the cause of faulty illness beliefs and muscle deconditioning with only minor disturbances to the neuro-endocrine system to account for any discrete biological abnormality. This is not surprising... this is the ideology of psychiatry - to formulate a psychological construct for symptoms they claim are "medically unexplained" or indeed "unexplainable".

Further more, thanks to the appalling state of the peer review system and the inherent bias of the BMJ/Lancet along with other journals overseas, much of this systematically biased research now increasingly described as "poorly carried out" has been published and pushed upon the medical establishment and the media in preference to *anything* that contradicts the views of the psychiatrists themselves. After all, if you say something often enough and in enough places - people start to believe it - to believe it to be true and as a result it becomes fact.

People with non-specific Fatigue Syndrome should by all means be seen by psychiatrists as primary care specialists... this is the correct speciality for treating mental and behavioural disorders.

(To the novice reader, any confusion over this situation has been created by the profession of psychiatry for the advantage of psychiatry.)

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**House of Lords Debate 16 April 2002 7.27 p.m.** by the Countess of Mar

Professor Wessely seems to have taken it upon himself to reclassify ME as a mental disorder in the WHO Guide to Mental Health in Primary Care in his capacity as a member of the UK WHO Collaborating Centre for Research and Training for Mental Health. He has disingenuously amalgamated his own definition of chronic fatigue syndrome with ME by stating that ME may be referred to as CFS and is thus, he claims, a mental disorder.

The report concedes that there is huge confusion surrounding terminology. In reality it is simple. In 1992, the WHO included the term CFS as one by which ME is sometimes known, and indeed many international researchers now refer to ME as CFS. The patients whom they are studying resemble those with neurological illness. There is a long established acceptance that such patients are severely physically ill. However, since 1991, Wessely and his colleagues have been responsible for producing their own criteria for CFS, known as the Oxford criteria. They dropped all reference to physical signs. Physical symptoms suddenly became behavioural in origin as opposed to organic.

The scientific evidence is that, at best, a total of between 22 and 28 people with CFS and no psychiatric illness have derived limited benefit from CBT—nine of them in just two trials. None of the trials studied those with ME who were severely affected or children. Professor Friedberg of State University, New York, says that, for those CFS individuals who do not have psychologically mediated reductions in inactivity, such a directed approach as CBT would be inappropriate and counterproductive.

Is the Minister happy to rely on such manipulation of the scientific evidence as appears in the report? Does he endorse management recommendations for patients with ME who do not have psychiatric illness that have been extrapolated from findings of studies on patients with a psychiatric diagnosis?

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**BBC Panorama 'Sick and Tired'.**

The investigative Panorama TV programme reveals the results of an exclusively commissioned survey which shows children are being pressurised into accepting psychological treatment.

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**Risks associated with exercise programmes need to be recognised and investigated further**

When referring to cognitive behaviour therapy and graded exercise therapy, they mention findings which they claim show that "the benefits ... outweigh the risks in ambulant adult patients". I think the risks involved in somebody with ME doing graded exercise programmes need to be investigated further. Is it worth a percentage of patients becoming severely (and often chronically) affected following graded exercise therapy programmes (2) so that some other patients, who may never have had strictly-defined ME but some fatigue syndrome which does not have an abnormal physiological response to exercise, can benefit?
WARNING: UK Prime Minister’s Strategy Unit on Mental Health
Eileen Marshall and Margaret Williams, 26th May 2005

It remains beyond comprehension how any “Strategy Unit”, especially one at Prime Ministerial level, feels able to ignore the published evidence about the organic basis of ME/ICD-CFS that has been repeatedly put before the Prime Minister, Ministers of State, the Chief Medical Officer, the Chief Executive Officer of the Medical Research Council and the Lord Chief Justice, to name but a few to whom convincing evidence has been sent. That evidence includes proof of an organic pathoetiology causing disruption of virtually all the major systems of the body, most notably the neurological, immunological, cardiovascular, respiratory, musculoskeletal and gastrointestinal systems, yet the State officials (and the psychiatrists who advise them) who determine what is or is not a “mental health” disorder seem determined to lump together all states of so-called medically unexplained “chronic fatigue” without differentiation and to impose the same management regime of graded exercise upon one and all.

Patronising promises that this regime will be “gentle” and will let the patient set the pace and that they can withdraw at any time are only for the gullible, because if patients do withdraw, they will automatically lose their right to state benefit and there is already evidence that in an existing clinic, CBT is being used to convince patients that their pain, insomnia, gut problems and allergies are simply somatisation and that these symptoms will resolve once a correct mode of thinking is achieved. There is also a worrying obsession with the patients’ sex lives. Patients are told that using a support group is a retrograde step and are advised against it, and there is a refusal to refer people to a pain clinic or to offer any care other than anti-depressants. Is this just what the Prime Minister’s Strategy Unit hoped for?

RiME Latest - 27th January 2005

The APPG Chair is now supporting the very psychiatric psychological modes of treatment which he condemned in 1999. He now says that GE and CBT do help people with ME (letter to severely affected person with ME Dec. 2003, letter to relative of ME patient Aug. 2003): his source - The York Review:

The York Review did virtually all the work re. the CMO Report on ‘CFS/ME’ (The APPG Chair, incidentally, endorses the latter report and now uses the term ‘CFS/ME’). The Review drew heavily on the work of Wessely, (‘much of the database was provided by.. Wessely’ - CMO, Sept. 1999) and like-minded colleagues and reported promising results for GE and CBT. Studies which challenged the role of GE and CBT were excluded; and there was not one study on severely affected people with ME.

Many of the references in The Royal Colleges Report which Mr Wright condemned 1999, written or co-authored by Wessely, correspond to those in the York Review which he cites; so do other references, written or co-authored by members of the ‘Wessely School’, eg Sharpe and Chalder.

Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: randomised controlled trial [Reply to Gijs Bleijenberg and Stulemeijer et al., BMJ 330 (7481) 14. by Steven Du Pre]

I would like to point out the inaccuracies inherent in the following statement by Professor Bleijenberg and his colleagues: “A characteristic belief of patients with chronic fatigue syndrome, especially in case of passive patients, is that fatigue is made worse by exercise. This cognition, although functional in the first phase of the condition, is dysfunctional in the longer term and maintains activity avoidance and symptoms.”

This statement exhibits a misunderstanding of the disease Myalgic Encephalomyelitis/CFS as a recoverable, psychological condition. The exact opposite is true about this disease---it is a non-recoverable, physically debilitating disease (the largest study done by Dr. Leonard Jason shows a 4-8% recovery rate). And the disorder is clearly not fatigue, but is more accurately represented as muscle myopathy, reduced oxidative muscle metabolism, and cardiac insufficiency (see references below which substantiate this assertion).

Bleijenberg and his colleagues are bypassing solid, substantive studies which counter their statements about Myalgic Encephalomyelitis/CFS. The end result of this is undue suffering in the patient community and an unjust portrayal which undermines the reality of the seriousness of this neuroimmune disease which has been correctly classified in the ICD since 1969 as a neurological disorder, which is worsened by aerobic exercise as shown
clearly in the brain SPECT scan evidence in Dr. Byron Hyde's book, The Clinical and Scientific Basis for Myalgic Encephalomyelitis/CFS.

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**A systematic evaluation of the quality of meta-analyses in the critical care literature** From Jerry Campbell

I believe that this article may be of general interest, given that there is at least one meta-analysis that supports CBT and graded exercise in CFS. The results of this paper suggest that over half of published meta-analyses have major flaws.

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**Campaigning for Research into Myalgic Encephalomyelitis – 2004**

What follows are the first three pages of RiME's Autumn 2004 Newsletter. We don't believe that the new NHS Centres will be in the interests of the vast majority with ME and urge people to protest now. Nor do we believe the prospective PACE and FINE Trials will benefit the vast majority who are severely affected with ME and urge people to make their protests now. Those who hold power at Westminster are doing all they can to close the door on genuine ME activists with legitimate concerns and grievances.

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**25% ME Group Response to the CFS/ME Research Advisory Group’s Draft Report** "CFS/ME Research Strategy (Draft Document for Public Consultation)"

We do not believe that GET, CBT or even pacing will stop the disease! We should be seriously investigating the pathophysiological processes that are causing people to deteriorate.

The only point we would make regarding Para 157 would be that there is strong evidence from patient-reporting groups and documentation from various sources confirming that GET does make patients with Myalgic Encephalomyelitis worse (but this does not necessarily apply to patients with CFS and other Functional Somatic Syndromes). Relapses in patients with ME can last for months, years, or for the lifetime of the patient. For patients whose lives are already devastated by ME, the additional level of suffering caused by this form of "treatment" can often be intolerable.

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**Colin Blakemore on BBC Radio 5 Live** by Stephen Ralph

The current agenda of drowning us all in Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) will neither cure or rehabilitate people who are chronically ill with Myalgic Encephalomyelitis.

It has already been pointed out many many times in patient surveys carried out by ME charities including one by Action for ME and another by the 25% ME Group that people with ME who have already tried CBT and GET either have been harmed by such regimes or have found little or no use for such "treatments".

Until last year, many millions of pounds had already been spent on studies relating to CBT and GET on people with Chronic Fatigue Syndrome.

Such studies always had mixed outcomes because the patient groups utilised for such studies were (by virtue of the clinical inclusion criteria used) a heterogeneous group of patients.

Last year over £8 million was given to the same psychiatrists who are now carrying out yet more of the same studies using the same clinical criteria which will thus produce yet more mixed research results and leave many thousands of people with ME bereft of a cure or any sort of functional recovery.

Many see the current agenda as a process by which career psychiatrists can earn moneys from MRC handouts - cornering the market in ME/CFS treatments so that they can in fact become the default clinical specialist for people with ME.

In effect, ME/CFS will become a psychiatric disorder; treated by default and exclusively in a psychiatric setting. This is of course totally supported by the UK's biggest ME charities Action for ME, the ME Association and AYME. The bottom line is,... when those with chronic tiredness have been cured by CBT and GET there will be a
core group of very sick and disabled people with all the signs and symptoms of Myalgic Encephalomyelitis who will have gained NOTHING from the process forced through in the UK over the last 5 years.


The guidelines present CBT and graded aerobic exercise therapy almost as a panacea for CFS. General practitioners who adopt these approaches, and who are seduced by the upbeat mood of this section of the guidelines (and who do not refer to the original references), may tend to push their CFS patients to do more if they are not improving during and after treatment. This could be highly detrimental to some people with CFS.

The Harm suffered by many people because of a psychiatric diagnosis is a well-kept secret

Quote: People--even many psychotherapists--often assume that psychiatric diagnosis is a science. The fact is, however, that very little solid science goes into the creation of categories of psychiatric diagnosis or the application of them to patients. When science is absent, every conceivable kind of bias can enter in to decisions about who is diagnosed as mentally ill and which label they are given.

An interview with Prof. Tony Pinching [1]

An interview with Prof. Tony Pinching [2]

I spoke to Prof. Pinching in 1998, when I was trying to get to see an ME specialist, privately. I needed to get a private referral because my GP would only send me to a psychiatrist, on the basis that my illness was precipitated/cause by a psychological trauma about which I was supposed to be in "denial" because I have "repressed" the memory of that event from my conscious mind. My GP, however, wanted me to name the trauma so he could arrange the appropriate "help" for me from a psychiatrist. My GP at one time thought that I may have Hysterical Conversion Disorder. There was, and indeed is, no such trauma, but he would not believe that. If I went to his psychiatrist, then it would be on the basis of my confession to a trauma I did not have. I would be damned by that confession. If I had refused to play the "name the trauma game" with my GP, then he would simply have condemned me for not cooperating with him and would sever all support and assistance, including his refusal to answer letters from all and sundry, including local authority Councillors and even my MP.

PRiME - Sending Us Around in Circles Stephen Ralph 19th June 2005

I understand that ever since the last issue of the WHO International Classification of Diseases was published, Simon Wessely and his colleagues currently pursuing the PACE and FINE trials - paid for by the MRC - have also been attempting to revise the next World Health Organisation International Classification of Diseases to include a new section covering Somatoform Disorders.

The aim of this plan is to formally reclassify "CFS/ME" as a psychiatric somatoform disorder along with other conditions that the psychiatrists deem to be equal or the same including conditions such as Fibromyalgia.

This is why the PACE trial - set up by the MRC - will not distinguish the difference between medical conditions such as what it has chosen to call the heterogeneously grouped disorder "CFS/ME" and Fibromyalgia when it selected patients. This is why the MRC will not follow the view that ICD ME/CFS/PVFS is a neurological disease despite the fact that the Department of Health has to respect the WHO ICD-10 classification that specifically states the opposite.

The MRC are ignoring the rules to promote their own beliefs.

"Power Interest and Psychology" Smail D 2005 BMJ Book review - "Selling Sickness: How Drug Companies Are Turning Us All Into Patients", comments by Douglas T Fraser
'With reference to Dr Fitzpatrick’s remark that myalgic encephalomyelitis is "not linked to any specific drug treatment", I should like to point out however that it is linked, in the minds of some, to non-drug "treatments" dubbed Cognitive Behavioural Therapy and Graded Exercise.

One authority, Professor Simon Wessely (1), has stated that neither are "remotely curative" and are only "modestly effective", while another, Professor David Smail (2) has commented that "CBT - in fact more a kind of rhetorical construction that a serious, theory-based practice - is perhaps the least convincing of all therapies from the standpoint of a critical onlooker. In combining the 'scientific rigour' of behaviourism, with the mentalism of, essentially, popular psychology, CBT is par excellence the product of professional interest....supported by its doctors through the judicious highlighting of a handful of research studies from the huge, chaotic and contradictory literature that has developed in the psychotherapy field over the past fifty years or so."

Squaring the Circle: Disturbing discrepancies in statements made by Professor Simon Wessely in relation to ME/CFS: some questions and answers of which the Gibson Parliamentary Inquiry needs to be aware (Word format) by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams, 4th January 2006

It is a matter of record that the most severely affected (ie. those requiring DVs) are excluded from study in the UK and the Report of 2002 to the Chief Medical Officer noted this, as did the Systematic Review (2001) carried out by the Centre for Reviews and Dissemination at York University that informed the CMO’s Working Group report: (“In some studies participants were only eligible if they could physically get to the clinic. Those unable to walk or to get out of bed were automatically excluded, so it is not possible to assess whether [behavioural therapy] would be effective or even hazardous for a more severely disabled group of people”).

Moreover, the severely affected are excluded from the MRC current PACE “CFS/ME” trial (the management of which is directed by Wessely, who is also responsible for randomisation and database design): “Exclusion criteria: subjects unable either to attend hospital reliably or to do therapies” (ref: Trial Identifier: 3.6). The Trial Identifier is clear (at 3.4) that: “CBT (cognitive behavioural therapy) will be based on the illness model of fear avoidance” and that “GET (graded exercise therapy) will be based on the illness model of both de-conditioning and exercise avoidance”, neither of which occurs in authentic ME: studies that specifically set out to demonstrate de-conditioning (for example, Bazelmans et al: Psychological Medicine 2001:31:107-114) and exercise phobia (for example, Gallagher AM et al: Journal of Psychosomatic Research 2005:58:4:367-373) failed to do so.

It is a matter of deep concern that patients with fibromyalgia are to be intentionally included in the MRC PACE trials on “CFS/ME”, the results of which will then be proclaimed to be referring to those with “CFS/ME” (see attached Appendix containing information that was sent to the MRC but was ignored).

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”.

Chronic “fatigue” is not ME/CFS, but it is these Oxford criteria that have been, and continue to be, used by Wessely School psychiatrists who refer to “CFS/ME”: the current MRC PACE trials use the Oxford criteria, even though it is almost unheard of for studies to use criteria that have been superceded, as is the case with the Oxford criteria. By using the Oxford criteria, the Wessely School aim of drawing in as many people as possible is more readily achieved: the MRC CFS/ME Trial Identifier is quite clear that this is the intention: “We chose these broad criteria in order to enhance recruitment” (RCT of Cognitive Behavioural Therapy, Graded Exercise and Pacing versus usual medical care for the Chronic Fatigue Syndrome”). To intentionally mix patient populations does not accord with a rigorous scientific process, yet the Wessely School proposal was approved by the MRC, which inevitably raises questions of a pre-determined agenda.

Conflicting Concepts? Eileen Marshall and Margaret Williams, 28th May 2005

Of particular note is the use of the word “autonomy”: it seems that whereas Sir Donald’s intention is to increase all patients’ autonomy by involving them as fully as they wish in decisions about their medical care, the Prime Minister’s Strategy Unit is intent on removing ME/ICD-CFS patients’ autonomy by the pre-determined political tactic of classifying them as “mental” patients who are not to be allowed any investigations other than basic screening.

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Does Sir Donald’s “professionalism” include the requirement for doctors to keep up-to-date with evolving scientific evidence about “controversial” disorders such as ME/ICD-CFS so that sufferers are no longer wrongly deprived of their basic rights by doctors who are intent on furthering their own careers at the expense of patients, even to the extent that (against sound evidence which these doctors continue to ignore) they deliberately create “mental” disorders designed to require “lifestyle” interventions that do not work?

The problem is that in the real world, as Sir Donald must know, Government propaganda does not equate with Government policy, and it is policy, not “professionalism”, that ultimately decides how patients are treated, as many ME patients already know to their cost and as many more will doubtless soon discover.

An Inquiry by the UK House of Commons Health Select Committee into the Influence of the Pharmaceutical Industry by Margaret Williams, 28th October 2004

Given the well-known and long-term involvement with the pharmaceutical industry of certain medical advisers prominent in the ME world, the international ME community may be interested in this Inquiry.


In their letter, Abbot and Spence note that Prins et al focused on only one model of the disorder --- the psychosocial model --- and disregarded the abundant (and ever increasing) evidence of measurable biomedical anomalies in (ME)CFS.

Further, Abbot and Spence point out the reliable evidence-base that shows the number of trials using cognitive behavioural therapy in (ME)CFS to consist of only 8 trials, of which 3 resulted in a negative outcome, leaving just 5 studies that claim modest benefit.

The response from Prins et al to Abbot and Spence is astonishing: "We strongly disagree with Neil Abbot and Vance Spence's one-sided biomedical point of view". Who is being "one-sided" if not the proponents of the psychosocial model?

[It is also very unlikely that any of those who saw benefit had M.E. and not merely ‘chronic fatigue’.]

Some facts about CBT & GET Stephen Ralph

CBT and GET are the favourite therapies of the psychiatric ME/CFS school, while ME and CFS are classified under ICD - G93.3 as diseases of the nervous system and not mental and behavioural disorders. Based on biased research from the university Nijmegen (the Prins study [1] that used the CDC criteria for prolonged fatigue but eliminated the other CDC criteria), the Dutch Government has decided to start a trial implementation of CBT and GET in the Netherlands. I advise all ME patients, who will become worse after this therapy to bring a charge against the Government and to submit a claim for compensation.

NHS ‘CFS/ME’ Centres Condemned (RiME Newsletter Autumn 2005)

Extracts from letters sent to West Kent Health Officials: Sevenoaks:

‘.... ME and Chronic fatigue are being lumped together.... The CFS Service says it will treat 'CFS/ME' with CBT sessions.. by a psychologist.. This appears to have all the hallmarks of the 'Wessely School of Psychiatrists'. There would appear to be an erroneous assumption that PWME per se have low self-esteem and motivation, and negative thoughts, and therefore become inactive... this is not the case....’

Submission to the RACP Working Group regarding the Chronic Fatigue Syndrome Draft Clinical Practice Guidelines (PDF) Author: Dr Mark Donohoe MB BS Monday, 23 February 1998
ON CBT: ‘The recurrent theme of the relationship between belief in the exclusively physical nature of the illness and poor prognosis is grossly flawed, and cannot be supported by studies (even those which purport to confirm this view) or by logic. I wish to address this once here, so that it can be referred to as it arises throughout the body of the DCPG.

And here is the problem with this whole process. Poor recovery is predicted not so much by belief in the physical nature of the disease, as by a failure to adopt the peculiar (and often demonstrably faulty) beliefs of the doctor or experimenter!’

CBT, as practiced and researched to date, is a philosophical rather than a scientific construct. Definitions, methods, mechanisms and hypotheses are totally lacking, the experimental processes are not subject to placebo control (since the mechanism is unknown, there is no way to isolate the useful aspects of the process), and poor outcomes are ascribed to faulty beliefs on the part of the patient.

Worse, suffering people who do not fit the philosophy are subtly blamed for holding inappropriate beliefs which prevent a recovery which would otherwise have been achieved. The support of CBT by the WG is the rough equivalent of proposing ‘faith healing; in CFS.’

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FOR UK PARLIAMENTARY INQUIRY INTO ME/CFS Chronological list of documents relevant to the Inquiry, authored by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams, 7th November 2005

Most of the articles mentioned in this document are on the internet; all are available from Malcolm Hooper, Emeritus Professor of Medicinal Chemistry, Department of Life Sciences, University of Sunderland, SR2 7EE, UK.

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A FINAL FAREWELL TO THE PSYCHIATRIC FALLACY? By Margaret Williams, 13th August 2005

Given so much evidence of serious organic pathology in ME/CFS, perhaps psychiatrist Professor Michael Sharpe of Edinburgh needs to re-think his previous pronouncement that “Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and our health service” (lecture given in October 1999 hosted by the University of Strathclyde).

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High Standards at the MRC By Eileen Marshall and Margaret Williams, 21st April 2005

Firstly, Simon Burden wrote: “When researchers put together a proposal they are required to define the population they are studying”. Indeed so: why, therefore, does this basic requirement not apply to the PACE trials? And why is the MRC content with the confusing lack of definition for entry criteria into these trials for patients with what the MRC itself refers to as “CFS/ME”?

If those involved with the PACE trials adhere (as required) to the Trial Identifier and select their participants by using the Oxford criteria, then, by definition as set out in the Oxford criteria themselves, those with ME will be excluded from the start, and this is unequivocal. If there is no such strict adherence to the entry criteria, then the results will be flawed from the outset and therefore meaningless (and yet more millions of pounds will have been wasted). Either the criteria are adhered to, or the results will be flawed: there is no other scientifically credible interpretation.

How does this accord with the MRC’s apparent requirement for “the high scientific standard required for funding”?

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CDC Provides Clarification At Last by Margaret Williams, 26th April 2005

It is noted that the Centres for Disease Control (CDC) Media Relations Office appears to have provided official confirmation that “CFS” (chronic fatigue syndrome) is not the same disorder as myalgic encephalomyelitis (ME). This clarification has been reported via the US Newswire (see Co-Cure, 26th April 2005).
This confirmation would seem to be an important breakthrough in the confusion that surrounds the heterogeneous label “CFS”.

**RiME - Research into Myalgic Encephalomyelitis Sample letters from January to June 2002**

‘ME is a neurological illness, and is classified as such by the World Health Organisation. A substantial body of biomedical research (mostly carried out in the U.S.) Has demonstrated physical abnormalities in both the Central Nervous System and the Musculoskeletal, Cardiovascular, Immune and Endocrine systems.

A small number of studies have been earned out in the U.K., but in a piecemeal fashion and funded on a shoestring solely by charities and private donations. It is utterly unrealistic to expect that small charities can find the sums of money required for serious research.

Despite this, the DOH has funded nothing other than psychological psychiatric research into this illness. This is utterly inappropriate, as shown by the facts that despite millions of pounds of backing (mostly via the Linbury Trust); this approach has failed to advance knowledge of the cause and effective treatment of M.E. On the contrary, it has done nothing other than falsely portray M.E. patients as suffering from a psychiatric disorder. This has resulted in inappropriate and harmful treatment, and denial of basic social security benefits. This has lead to great distress and unnecessary suffering for many patients already struggling under the terrible burden of illness.

This shameful situation should not be allowed to continue. M.E. is not a mental health issue, and it is therefore imperative that research into the biological causes of, and treatment for, M.E. is undertaken, and that psychological / psychiatric research should not be considered, by the MRC.

**Dangers of Fad Treatments by Del Kennedy**

It is all too common to hear stories of desperate sufferers trying anything, no matter how bizarre or unlikely, in search of something that will make their lives bearable. And there are all too many practitioners ready to peddle nonsense if it makes them a good living.

At best, these 'treatments' do nothing at all. At worst, they can do a great deal of harm. I'm sure you will have recognised by now what I'm talking about: 'physicians' pushing quack 'therapies' like Graded Excercise and Cognitive Behaviour Therapy.

"To imply that the physical illness ME can be successfully treated by 'challenging negative thoughts' is an insult to people like my daughter who have been severely affected by the illness for many years and yet still retain a positive and realistic attitude. My daughter's condition deteriorated to an alarming degree after following a CBT & graded excercise approach."

**Pinching’s Perception? by Eileen Marshall and Margaret Williams, 20th January 2006**

The recently-released Minutes of the UK All Party Parliamentary Group on ME of the meeting held on 16th November 2005 contain a record of the presentation made at that meeting by Professor Tony Pinching, Associate Dean for Cornwall at the Peninsula Medical School and Chair of the NHS CFS/ME Service Investment Steering Group. It is this Steering Group that defined the criteria for the new “CFS” Centres in the UK; it also oversaw the bidding for and the allocation of the £8.5 million of Government funding. Thus, as Chair of the CFS/ME Service Investment Steering Group, a heavy weight of accountability rests on Pinching’s shoulders.

One can but ask yet again why someone in a position of such responsibility as Professor Pinching appears to be intent on wilfully ignoring the large body of international researchers calling for sub-grouping of “CFS” as a matter of urgency.

**For the attention of All Members of Parliament - Old and New** Margaret Williams 4th May 2005

Tomorrow, on 5th May 2005, the results of the UK General Election will be known: this may lead to either the return or replacement of Members of Parliament, and Parliament will sit on 11th May solely for the swearing-in of new MPs. Whatever the outcome, as soon as Parliament resumes, as many as possible of the ME community are
A CBT and GET database

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urged to contact their MP and to insist on their seeking and obtaining from the Minister of State for Health acceptable answers to a few straightforward questions:

Why are sufferers of myalgic encephalomyelitis (ME --- also known by the World Health Organisation as chronic fatigue syndrome or CFS) being offered only inappropriate and potentially damaging psychiatric interventions suitable for somatisation disorders when there is no evidence whatever that ME (as distinct from chronic “fatigue”) is a psychiatric disorder?

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PSYCHOSOCIAL TORTURE UK
The case of an ME/CFS child literally tortured by the UK psychiatrists.

I am writing to tell you what I know about Dr Trudie Chalder. She was consulted about the treatment of my son whilst he was in hospital. My son, who is 20 now, was admitted to a hospital in the District for rehabilitation with his ME. He was severely affected and bedbound and unable to care for himself. Since his discharge I have obtained the medical records and I can see that the consultant in charge wrote to Dr Simon Wessely for advice. I presume he referred the request to his colleague Dr Chalder. On my son’s hospital file is a document, dated 07-03-01, a ‘Draft Action Plan Proposal following consultation with Trudie Chalder’ which I attach. I find the action plan shocking, and I was particularly disturbed by the penultimate paragraph which states:

"We expect (name) to protest as well as the activity causing him a lot of pain. This may result in screams... it may feel punitive."

Letter to the BMJ by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams re: NICE 24th January 2006

Some of your readers may not be aware that in one particular disorder (ME/CFS - myalgic encephalomyelitis / chronic fatigue syndrome) for which NICE is currently compiling guidelines that are due early in 2007, on the influence of its advisors NICE is restricting itself to RCTs.

Most of the very few RCTs available have been carried out in the UK by those same NICE advisors themselves. Despite the fact that ME has been classified as a neurological disorder in the ICD since 1969 where it is also called CFS as well as PVFS (postviral fatigue syndrome) the NICE advisors believe it to be a behavioural disorder. For almost two decades they have disregarded the significant body of international evidence of its organic pathoaetiology. The lead proponent of the psychosocial model is Professor Simon Wessely of GKT School of Medicine.

We maintain it is important that none of the NICE guidelines should over-ride the empirical evidence, but in the case of ME/CFS, this is what is happening.

Such is the tide of public and professional concern about the misinformation that currently surrounds ME/CFS - which includes the Systematic Review carried out in October 2005 by Bagnall et al from the Centre for Reviews and Dissemination at York specifically to support the forthcoming NICE guidelines -- that a Parliamentary Inquiry chaired by Dr Ian Gibson MP has been established. Over 100 people, including patients and professionals, have already submitted evidence. Should you wish to access some of these submissions, they are available at http://www.25megroup.org

Problems and Solutions? by Eileen Marshall and Margaret Williams, 23rd February 2005

Such is the influence of these psychiatrists that they have recently secured funding of £11.1 million (including £2.6 million from the MRC) to carry out more “research” in an attempt to legitimise their own beliefs that ME does not exist except as an aberrant belief in the mind of suggestible patients and naïve doctors and to demonstrate that “ME” is in reality “chronic, medically unexplained fatigue” and as such is a mental health problem. It was in 1987 that the bid for the take-over of the severely incapacitating and discrete neurological disorder ME was effectively launched by certain psychiatrists and others on both sides of the Atlantic who were involved with the medical insurance industry; in this bid, the specific and WHO classified disorder was deliberately subsumed under the heterogeneous label of “CFS”, which in turn was destined to become a catch-all label for the so-called “medically unexplained symptoms” that have been shown to be either virally or chemically induced and which
were rapidly escalating out of control and becoming a serious financial threat not only to governments but also to the medical insurance industry.

Since 1987, the leitmotiv of the psychiatric literature on ME/ICD-CFS has been that patients who present with and suffer from a disorder that the psychiatrists and their corporate masters wish to eradicate are an “unjustified” and “underserving” financial burden and that it is neither cost-effective, necessary nor appropriate to investigate their “non-existent” disorder. Instead, patients’ “dysfunctional thinking” and their “personality problems” must be managed by psychiatrists.

This project has been remarkably rewarding to these psychiatrists and their respective departments, since they have received many millions of pounds sterling, not only from private charities such as the Sainsbury (supermarket) Linbury Trust (who between 1991 and 1998 provided over £4 million) but also from the pharmaceutical industry, the medical insurance industry (with whom they are deeply involved), Government itself and the MRC.

Observations on the Chief Medical Officer's Working Group on CFS / ME on RiME

Do they know that most patients with severe CFS / ME have never been properly clinically examined in the first place? (Wessely’s 1991 definition criteria do not require or permit evidence of neurological dysfunction to be taken into account).

It is all a question of selection and definition of cases studied and published.

No normal person is opposed in principle to any treatment which may offer even a glimmer of respite from such dreadful suffering and quality of life. If GA or CBT helped, desperate people would be queuing up in droves. It is because it does not help, and because it actually makes some people worse, that it is met with such opposition.

Patients know that what world expert on CFS / ME Dr Paul Cheney says is right - "The most important thing about exercise is not to have them do aerobics exercise. I believe that even progressive aerobic exercise, especially in phase one and possibly in other phases is counterproductive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA".

This is the exact opposite of what Wessely et al believe: they urge patients to undergo exercise programmes, claiming that such programmes are beneficial and safe.

People have died after following such programmes, but because the evidence is "only anecdotal", it is ignored. Presumably no-one will heed it until there has been a replicated double-blind, placebo-controlled trial proving that, dear me, patients do die from inappropriate interventions.

The real point of all this is that anyone, whether medically qualified or not, who looks at the worldwide published evidence on the devastation caused by CFS / ME could not fail to realise that it is offensively inappropriate to suggest (let alone to forcibly promote) the notion that such catastrophic illness could be cured by (or amenable to) cognitive behavioural therapy. It is akin to suggesting that if an amputee will only let himself believe that he still has a limb, he will cease to be disabled.

By churning out endless papers which promote CBT as "treatment" for CFS / ME, Wessely is trashing and trivialising terrible human suffering and by his influence, UK patients and physicians are being deprived of access to current knowledge.

INFORMATION ON MYALGIC ENCEPHALOMYELITIS (ME) FOR THE USE OF THE MEDICAL RESEARCH COUNCIL (MRC) AND THE NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE (NICE) Margaret Williams, 25th June 2004

Based on the evidence known to have been submitted to each group, there is widespread belief that the arbiters of both the Chief Medical Officer’s Working Group Report on “CFS/ME” of January 2002 and the MRC’s Research Strategy Plan for “CFS/ME” of May 2003 complied with a pre-determined policy not to clarify in their reports the World Health Organisation classification of ME / CFS as a neurological disorder. Not only was there no clarification, the report for the CMO contained specific misinformation, namely that “CFS and ME are classified as distinct illnesses in the World Health Organisation's International Classification of Diseases” (CMO’s report, page 5, section1.4.1) and the MRC report stated that it relied upon the CMO’s report.
This was notable, since the WHO has classified ME as a neurological disorder since 1969 and in the current ICD (revision 10, 1992) the classification remains unambiguous, with ME/CFS being coded to G93.3 under Diseases of the Nervous System. Specifically, the G93.3 classification captures all listed terminologies for the disorder including ME, CFS and PVFS (postviral fatigue syndrome).

This ambivalence of classification in the CMO’s report and the MRC report was further exploited in 2000 by the deliberate inclusion of CFS/ME as a mental disorder in the Guide to Mental Health in Primary Care produced by the UK WHO Collaborating Centre at the Institute of Psychiatry where Professor Simon Wessely works. It is not permitted under WHO rules to move a condition from one chapter of the ICD to another; moreover the WHO does not classify diseases by practice specialities: they are placed within a chapter according to pathophysiology. It fell to the Countess of Mar to obtain a retraction in the form of a letter dated 11th February 2004 from the Health Minister, Lord Warner, who confirmed that “the WHO, the WHO Collaborating Centre and the Department of Health have now agreed a position on the classification of CFS/ME. The UK accepts ICD-10 (and) the Department accepts that it might have been clearer to say that chronic fatigue syndrome is indexed to the neurology chapter and fatigues states to the mental health chapter”.

This seemed clear enough, but a letter dated 31st March 2004 from Karen Nicolaysen in the Research and Development section of the Department of Health states that the Department is “neutral on this issue”. Further, when the Countess of Mar asked the question “Whether, in the light of their clarification that ME/CFS is a neurological disease and not a psychiatric disorder, (Her Majesty’s Government) will forward this information to the chief executives of all NHS healthcare trusts”, the reply on 20th April 2004 from Lord Warner was semantic: “The Department of Health did not say that ME/CFS is a neurological disease”. We are therefore left with confirmation that the Department of Health accepts that ME/CFS is a classified neurological disorder but that the Department does not accept that it is a neurological disorder.
4: A summary of the available medical research
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Taken from www.hfme.org

What is known medically and scientifically about M.E. so far?
Despite popular opinion, Myalgic Encephalomyelitis is not ‘medically unexplained’ nor ‘mysterious.’ There 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 misdiagnosis.

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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.

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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 musculoskeletal 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)

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there is evidence that natural killer (NK) cell activity is impaired (i.e. diminished)
there is evidence that the vascular biology is abnormal, with disrupted endothelial function
there is novel evidence of significantly elevated levels of isoprostanes
there is evidence of cardiac insufficiency and that patients are in a form of cardiac failure (which is exacerbated by even trivial levels of physical activity, cognitive activity and orthostatic stress)
there is evidence of autonomic dysfunction (especially thermodyssregulation; 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 of 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:
27. An acute onset (biphasic) epidemic or endemic infectious disease process
28. An autoimmune disease (with similarities to Lupus)
29. An infectious neurological disease, affecting adults and children
30. A disease which involves significant (and at times profound) cognitive impairment/dysfunction
31. A persistent viral infection (due to an enterovirus; the same type of virus which causes poliomyelitis and post-polio syndrome)
32. A diffuse and measurable injury to the vascular system of the central nervous system (the brain)
33. A central nervous system (CNS) disease (with similarities to MS)
34. A variable (but always, serious) diffuse (acquired) brain injury
35. A systemic illness (associated with organ pathology; particularly cardiac)
36. A vascular disease
37. A cardiovascular disease
38. A type of cardiac insufficiency
39. A mitochondrial disease
40. A metabolic disorder
41. A musculo-skeletal disorder
42. A neuroendocrine disease
43. A seizure disorder
44. A sleep disorder
45. A gastrointestinal disorder
46. A respiratory disorder
47. An allergic disorder
48. A pain disorder
49. A life-altering disease
50. A chronic or lifeleng disease associated with a high level of disability
51. An unstable disease; from one hour/day/week or month to the next
52. 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:

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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


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 EncephalomyelitisEdited 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:


Sample articles….

Influence of exhaustive treadmill exercise on cognitive functioning in chronic fatigue syndrome. La Manca JJ; Sisto SA; De Luca J; Johnson SK; Lange G; Pareja J; Cook S; Natelson BH C.F.S.

‘We conclude that after physically demanding exercise, CFS subjects demonstrated impaired cognitive processing compared with healthy individuals.’


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'Using this method, although there was significantly less vagal power in the sitting versus the standing postures for both groups, the overall vagal power was significantly lower (p < 0.034) in the CFS group versus healthy controls. Vagal power was also significantly lower (p < 0.01 to p < 0.05) at all breathing rates in both postures except while standing and breathing at 18 breaths/min.

Exercise responsive genes measured in peripheral blood of women with Chronic Fatigue Syndrome and matched control subjects. Whistler T, Jones JF, Unger ER, Vernon SD. Journal: BMC Physiol. 2005 Mar 24;5(1):5 PMID: 15790422

‘Exercise-responsive genes differed between CFS cases and controls. These were in genes classified in chromatin and nucleosome assembly, cytoplasmic vesicles, membrane transport, and G protein-coupled receptor ontologies. Differences in ion transport activity/ion channel activity were evident at baseline and were exaggerated after exercise as evidenced by greater numbers of differentially genes in these molecular functions.’

A measure of heart rate variability is sensitive to orthostatic challenge in women with chronic fatigue syndrome. Yamamoto Y, LaManca JJ, Natelson BH.

‘The specificity in differentiating CFS from controls were 90% and 72%, respectively. The data suggest that a decrease in aperiodic fractal component of HRV in response to HUT can be used to differentiate patients with CFS from CON.’


Circulating Blood Volume in Chronic Fatigue Syndrome. David H. P. Streeten, MB, DPhil, FRCP, FACPR. David S. Bell, MD, FAAP

Of the 19 patients reported here, abnormalities in blood volume were very common. The most common, found in 16 of 19 patients, was a reduction in red blood cell mass. Eleven subjects had low plasma volumes, and total circulating blood volume was subnormal in 12 of 19 subjects. In some individuals this abnormality was strikingly severe. Patient #15, for example, had an RBC mass of 12.9 mL/Kg, which is 46% of the expected normal, and a total blood volume of 35.8 mL/Kg, which represents 49.7% of the expected normal value (21).

In general, blood pressure measurements were not predictive of the results of circulating blood volume measurements.

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, our 55.2% of patients who had a VO₂max of less than 20 mL/kg per minute correspond to class 3-4 on the disability scale, indicating moderate to severe impairment. CFS can and does result in prolonged debilitation.’

Respiratory symptoms and lung function testing in Chronic Fatigue Syndrome (CFS) patients P. De Becker, I. Campine, E. Van Steenberge, M. Noppen, A. Leysl, K. De Meirleir

‘CFS patients show a significant decrease in VC, possibly due to a significant increase of RV. The incidence of bronchial hyper-responsiveness in this group is also remarkably high. These observations can, at least partially, explain the respiratory symptoms in these patients.’

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.’

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.’

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.’


‘The elevated RNase L group had a lower peak VO2 and duration than the normal group, but a higher KPS. The results suggest that both exercise testing and the RNase L biomarker have potential to aid in the diagnosis of CFS.’

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 I muscle fibres.’


‘The patients with CFS all had abnormal Holter readings’

‘We further report the occurrence of mild left ventricular dysfunction in 8 of 60 patients in continuing studies of this population with CFS, younger than 50 years old, and with no risk factors for coronary artery disease. All 60 patients with CFS showed repetitively flat to inverted T waves alternating with normal T waves.’

Complement activation in a model of chronic fatigue syndrome. Sorensen B, Streib JE, Strand M, Make B, Giclas PC, Flesher M, Jones JF. Department of Pediatrics, National Jewish Medical and Research Center, Denver, CO, USA.

‘Exercise challenge induced significant increases of the complement split product C4a, but not C3a or C5a, at 6 hours after exercise only in the CFS group (P <.01), regardless of allergy status. Mean symptom scores were significantly increased after exercise through the use of a daily diary (P <.03) and a weekly diary (P <.01) for the CFS group only.’
‘Exercise challenge may be a valuable tool in the development of diagnostic criteria and tests for CFS.’

CFS severity is related to reduced stroke volume and diminished blood pressure responses to mental stress
Arnold Peckerman, John J. LaManca, Sharon L. Smith, and Benjamin H. Natelson; NJ CFS Research Center, University of Medicine and Dentistry of New Jersey

‘An observation was made that in patients with CFS, a lower stroke volume was highly predictive (r = .72, p < .001) of illness severity. When divided into severe (N = 11) and less-than-severe (N = 10) groups, the severe CFS patients were found to have a lower stroke volume and cardiac output (p < .05) relative to a more moderate CFS group across three different postures.’

‘These findings suggest the possibility of a low flow circulatory state in the most severe cases of CFS. In patients with a less severe form of CFS, a diminished blood pressure response to a cognitive-behavioral (speech presentation), but not to an aversive-sensory (the cold pressor test) stressor may indicate a defect in the higher cortical modulation of cardiovascular autonomic control. In this latter group, situations may arise where a demand for blood flow to the brain may exceed the supply with a possibility of ischemia and a decrement of function.’

[Note that the so-called 'severe' patients in this study are in reality only mildly or possibly moderately ill]

Evaluating Blood Volume Studies - Some Thoughts David S. Bell, MD, FAAP Published in Lyndonville News, March 2000

'So far in our office we have measured the circulating blood volume in nearly fifty patients using the Chromium 51 method. It is essential that this method be employed (done in the nuclear medicine department of large University hospitals) as it is the only reliable method of assessing blood volume. There are two components of blood: the red blood cells and the plasma (fluid); everything else doesn't contribute much to the volume. The results are expressed as a function of body weight. Normal red blood cell mass should be between 23 and 28 ml/Kg, and the plasma volume should be between 40 and 52 ml/Kg. The total circulating blood volume is the sum of the two parts, and should lie between 60 and 80 ml/K.

Overall, about eighty percent of our patients with CFS have had either a low red blood cell mass, plasma volume, or both. Some patients have been extremely low, less than 50% of normal blood volume. To put this in perspective, if a healthy person were to bleed 40% of their volume out in a car accident it would likely be fatal. The loss in CFS is presumably gradual. The finding of decreased blood volume in CFS first came from Dr. David Streeten, and I am convinced it is accurate and will serve as a marker for the illness in some regard.'


‘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 neurophysiological, behavioral, and neuroendocrinological alterations often found in these patients.

Mitochondrial abnormalities in the postviral fatigue syndrome. Behan WM, More IA, Behan PO.

‘We found mild to severe atrophy of type II fibres in 39 biopsies, with a mild to moderate excess of lipid. On ultrastructural examination, 35 of these specimens showed branching and fusion of mitochondrial cristae. Mitochondrial degeneration was obvious in 40 of the biopsies with swelling, vacuolation, myelin figures and secondary lysosomes. These abnormalities were in obvious contrast to control biopsies, where even mild changes were rarely detected.’

In vivo magnetic resonance spectroscopy in chronic fatigue syndrome. Chaudhuri A, Behan PO.

‘Cell membrane oxidative stress may offer a common explanation for the observed MRS changes in the muscles and brain of CFS patients and this may have important therapeutic implications. As a research tool, MRS may be
used as an objective outcome measure in the intervention studies. In addition, regional brain 1H MRS has the potential for wider use to substantiate a clinical diagnosis of CFS from other disorders of unexplained chronic fatigue.¹

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**Impaired oxygen delivery to muscle in chronic fatigue syndrome.** McCully KK, Natelson BH

'In conclusion, oxygen delivery was reduced in CFS patients compared with that in sedentary controls. This result is consistent with previous studies showing abnormal autonomic control of blood flow.'

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**Post-viral fatigue syndrome: evidence for underlying organic disturbance in the muscle fibre.** Jamal GA, Hansen S.

'Ten patients with post-viral fatigue syndrome and abnormal serological, virological, immunological and histological studies were examined by the single-fibre electromyographic (EMG) technique after excluding concurrent problems in the neuromuscular system. No abnormality of fibre density was noted but all patients had abnormal jitter values. Very high jitter values were not associated with impulse or concomitant blocking. The findings confirm the organic nature of the disease.'

'This muscle membrane defect may be due to the effects of a persistent viral infection.'

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**Enteroviruses and postviral fatigue syndrome.** Behan PO, Behan WM, Gow JW, Cavanagh H, Gillespie S. Department of Neurology, University of Glasgow, UK.

'Postviral fatigue syndrome (PFS) occurs both in epidemics and sporadically. Many of the original epidemics were related to poliomyelitis outbreaks which either preceded or followed them. The core clinical symptoms are always the same.'

'We have detected enteroviral genome sequences in muscle biopsies from cases of PFS, using specific enteroviral oligonucleotide primers in the polymerase chain reaction (PCR). In addition, whole virus particles can be demonstrated in PCR-positive muscle, using solid-phase immuno-electron microscopy. An increase in the number and size of muscle mitochondria was found in 70% of PFS cases, suggesting an abnormality in metabolic function. Evidence of hypothalamic dysfunction was present, particularly involving 5-hydroxytryptamine metabolism. A putative model of PFS, based on persistent enteroviral infection in laboratory mice, revealed resolving inflammatory lesions in muscle with, however, a marked increase in the production of certain cytokines in the brain. This model may help to explain the pathogenesis of PFS.'

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**Specific oxidative alterations in vastus lateralis muscle of patients with the diagnosis of chronic fatigue syndrome** Stefania Fulle (a), Patrizia Mecocci (b), Giorgio Fano (c), Iacopo Vecchiet (d), Alba Vecchini (e), Delia Racciotti (d), Antonio Cherubini (b), Eligio Pizzigallo (d), Leonardo Vecchiet (c), Umberto Senin (b) and M. Flint Beal (f)

'From these results we hypothesize that in CFS there is oxidative stress in muscle, which results in an increase in antioxidant defenses. Furthermore, in muscle membranes, fluidity and fatty acid composition are significantly different in specimens from CFS patients as compared to controls and to patients suffering from fibromyalgia.'

'These data support an organic origin of CFS, in which muscle suffers oxidative damage.'
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 (Sussex 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. 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.

I have severe ME and have not attended a LP session. However, I did do a CBT (Cognitive Behaviour Therapy) course some years ago which was much cheaper (covered completely by my health fund, actually [1]) and sounds similar.

CBT was indeed useful, because it taught me ways to handle change. The things you believe, and thus your feelings which are based on them, and thus your thoughts which are based on those feelings, control your view of the world in the same way a camera view enlarges and shrinks. You might be peering at the world through a magnifying glass, or scanning it from a telescope, but CBT helps you get your view in balance.

For me, this change meant being able to maintain a more positive attitude in the face of suffering, value what I have left rather than agonizing over the huge amount I've lost, and manage my few available resources in a much more realistic way. I have techniques for dealing with the anxiety and lack of resilience caused by my illness. I can view my increasing disability with less helpless despair and more practical management. The CBT I received has really been helpful to me.

However, none of these powerful mental/emotional changes have had the least effect on my physical symptoms, only on the way I handle them. In fact, over the years I have continued to get physically worse, despite (and often due to) me putting everything I have into efforts to recover. I am grateful for the CBT techniques which help me deal with my situation, but I am very much concerned over any mental/emotional treatment which claims to heal physical damage.

I used to be a great believer in the ability of the human mind and the power of positive thinking. I had always applied my strength of mind to every problem I encountered, and it had always worked. It took me years to accept that it wasn't working with M.E. Even now, I keep wanting to believe it still works. It has been one of my most important principles.

But I have to accept the facts. Changes in belief, feeling and thought (including hypnosis) do not change physical realities. A person with a broken leg can indeed walk on that leg if they believe it's possible (I've seen this done), but the leg will remain broken and will in fact be damaged further by this act of belief.

A person diagnosed correctly with ME cannot change those realities with belief, however much we may desperately want to do so. The muscles which let go or spasm will still dump me on the floor or flick my cup of tea across the room. The damaged nerves will still shriek with pain, and I will still have to take medication and put a great deal of mental effort into managing that pain. Depleted organs will not start functioning correctly. Our immune system (which is usually overreacting, not underreacting) will not regulate itself according to what we believe. The cell-wall damage which progressively starves and poisons our bodies is so far from being affected by what we think and believe that we might as well be trying to rebuild the Berlin Wall with a pair of toothpicks.

LP can't change the physical realities of M.E. I wish it could.
Clytie Siddall -- Renmark, in the Riverland of South Australia

Apologies if this email is badly written or difficult to understand: due to illness, the writer has cognitive problems, has great difficulty typing and is severely debilitated.


[B] http://www.sayer.abel.co.uk/LP.html

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. & 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 won't do PWME much good.

Name: Harmony58*

Good mental health is best for everyone including doctors and therapists. The problem with this particular therapy is that the premise doesn't work with organic disease since the assumption is that if you change your thinking you change what is happening to you. The problem is that you cannot think your way out of any organic disease, not even the heartbreak of psoriasis.

Attitude changes can work wonders for most of us, not just our teenagers, but it doesn't cure biological disease. There are many much less expensive therapies that are a great deal more effective in helping people to cope with this devastating illness.

Name: Jaomi

I was made to try cbt by my doctor who referred me to a clinic who apparently "specialised" in cfs and cbt. I didn't like the course because it was set around the idea of having 4 thirty minute rest breaks everyday for the rest of your life (that's what the course I went on was anyway). I couldn't see how that was supposed to improve my life in any way. I’m unable to work with my current symptoms, but if having these rest breaks, even if my symptoms
improved, no employer is going to want someone who has to have 4 thirty minute rest breaks at the same times everyday no matter what. So I would be in a no better situation.

I also couldn’t cope with the idea that the illness was caused by overactivity as it was described in the group sessions I went to. This seems to blame the ill person for causing the illness and I don't agree with that. None the less I tried to stick with the program but found it impossible. It’s impossible to be able to take a break at the exact same time everyday, four times a day, there are too many variables to everyday life. Such as if someone visits, or there’s an emergency or if you have a child or anything. No healthy person needs this, neither do those with cfs, it just adds stress and removes hope indirectly by placing blame. I would not recommend it.

Name: Richard Country: UK

A parent's view - When my eldest daughter was finally diagnosed with ME (after 3 months of doubts and tests) we were given an appointment for what was planned to be the first of many CBT sessions.

I took my daughter along and we listened and the woman stared taking notes of my daughter's history - where she was born, what she did, what she liked, what her grandmother's name was, her grandfather etc. and started saying that she was looking also for any trauma which might have occurred. I listened and kept reasonably quiet, as I wanted my daughter (then 13) to explain.

This woman then asked to speak to my daughter alone.

We came away with a feeling that this was going nowhere.

I had already examined, with my wife, all of the past and tried to see what might have caused it, was there anything that had happened, or was happening, which might affect her health.

I look back now in amazement that I even countenanced any such session for what was and is a biological illness. But, and this is something I sometimes forget, I was a new parent of an young ME sufferer and I was going with what the hospital suggested - just following through and probably still dazed by all of this.

We didn't know about ME and we were looking for anything to help.

After coming away from that first meeting we discussed with my daughter we both agreed this was not what was needed. Apart from the exhausted she experienced in travelling there and back she felt it achieved nothing.

After all, any person with a modicum of common sense is going to analyse the situation and look for possible causes and then methods on how to deal with it. We don't need another acronym to help cope. We can do that ourselves.

We didn't repeat that experience. It was totally useless from our point of view and I had doubts on the skills or qualifications of the person giving this.

Isn't it coincidental that when they ask for 'volunteers' for money-wasters such as the PACE trials in the UK the people they want are 'new ME patients'? I.e those who have so little knowledge about ME and are probably still reeling from the sudden and devastating onset of a strange illness.

The psychiatrists really know something about manipulation.

Name: Owen* Country: UK

Firstly, It took 8 months to be diagnosed with ME/CFS. I was given counselling which I could barely attend and spent some of my sessions lying on the carpet of the psychologists floor. I had lots of blood tests etc. I was told that people with depression have high cortisol levels, that’s funny I said, I barely have any. Anyway I had to attend just to get some sick pay from work. I was then referred to Manchester and diagnosed with CFS, since then I have since I private doctor who says I have ME, not CFS, bloody confusing. Anyway I was given no decent advice and told I needed CBT/GET. I attended therapy and was told there was no way I could do GET. I had CBT instead, but it made me worse or no improvement, as I could barely speak. I consider CBT a waste of time for the patient and a waste of money for the NHS. It has not helped me/made me worse. I am bed bound/housebound under care of parents at 32 years old.
I would also like to say that on my health forms for insurance industry it was written anxiety/depression were objective symptoms chronic fatigue syndrome. Work that one out.

CBT/GET for ME patients is like giving psychological therapy to a cancer patient before they have had chemo.

Would it not be more appropriate to spend more money on providing care and medications to help recovery and then once better engage patient in neuropsychological therapy.

Name: Rob

The fact that people with CFS are referred for CBT, or any other kind of psychotherapy, as a treatment for their CFS makes as much sense as referring a diabetic. Yes, your way of thinking toward your illness can change, but I think the foremost reason people with CFS are referred for psychotherapy is the belief that it's all in the patient's head.

Comments from Greg Crowhurst of the 25% M.E. Group to the Gibson Enquiry: December 2005

A sufferer recounts the often horrifying impact of this “treatment” [CBT and GET] regime on those with severe ME:

“All of my 'help' is useless:

I am offered anti-depressants (I am not depressed)

I am offered 'Behavioural Therapy' (I have no incorrect illness beliefs).

I am offered 'Graded Exercise' (Which even in small moderation, relapses me).

EVEN WHEN I DO THESE ALL AGAINST MY WILL. As an inpatient in Hospital, my medical records are falsified, and it claims I am 'obstructive' to my own recovery, as these psychosomatic principles have no effect on me. This is then claimed to be MY fault, not the fact that I am not mentally ill, and therefore do not 'recover' from M.E via mental illness interventions’”.

The same sufferer goes on to tell how:

“I was refused medical drugs for chest pain and orthostatic intolerance (a feature of M.E) unless I agreed to be LOCKED in a mental institution in LONDON (National Hospital For Neurology & Neurosurgery) Summer 2004.

I participated in ALL activities I was asked to do, despite being mostly bed-bound.

I was not given food, and had to resort to hiding food in bags, and urinating in water bottles and hiding them under the bed (as I was refused to be pushed to the toilet).

Despite this treatment, I continued my 'Behavioural Therapy at this Hospital and did everything they asked. On reading my medical records, it stated 'had not engaged with the treatment protocol, and self-discharged'. All lies and fabrication of the truth

This is what 'Behavioural Therapy' is for an M.E patient in 2004 in the NHS”.

Name: A mother of a child with M.E. (name withheld) Country: Australia [Online]

‘My daughter developed kidney cancer at age 9. It was a very large cancer, very sudden. We were so shocked, the whole family. But we had a great deal of support, a whole support network, medical staff knowing exactly what was happening and helping us to understand, free accommodation and transport in the city (we are country people), and the support for my daughter herself was constant and so important: lots of positive support and friendliness from medical staff, whole areas set up for cancer kids, to make the experience less horrific, special
school provisions, from the beginning we had all the support we could possibly need. And that made all the difference.

Although we were still shocked and desperately worried, and it was a ghastly time, it was so much less of a strain on all of us because of the support we received. My daughter herself has very few bad memories of that time, and was able to remain positive throughout, and feel good about herself for being strong and fighting cancer.

However, she didn't get better. Her cancer results were good, but she was still sick, sicker really, because during the cancer treatment, she might be paralyzed by the chemo (it affected her nervous system), throwing up or feverish or in pain, but this came and went. The medical staff space out the treatment so it's doesn't wear you down too much. But now, she was just sick all the time, feverish, in pain, exhausted, dizzy, confused, and of course now we know that was ME. But then we had no idea.

And it started: instead of being the brave kid who had fought cancer so hard, she was a kid with problems. "So there are problems at school, huh? You're not doing well at school?" the doctors started saying in a very unpleasant way. She was really taken aback. She was extremely good at school and keen on everything. They knew that.

"So there are problems at home, huh? Something wrong in your family?" We couldn't win. If the doctors didn't understand it, then it was the child's fault. This is, I think, the cruellest thing that has happened to her. Her self-esteem was attacked, she was questioned repeatedly about personal things, and told she was sick because she didn't try hard enough, because she wasn't good at school, because she didn't want to be at school, because her family was bad, because she liked being sick.

These were so far from the truth, I was amazed that anyone could even imagine them. This was the same child who had struggled so hard with cancer, kept her chin up all the way, and been admired by the same medical staff for her courage, positive attitude, talents and emotional maturity. Now, being sick was her fault.

Cancer is vicious, but you die or get better, basically. Chemo is awful, but you don't suffer all the time, only in bouts of months. You are not suffering at a terminal level for decades, which is what happens with ME.

And you don't get blamed for this horrible thing that has happened to you. That is indeed the cruelest blow. My bright, happy, enthusiastic daughter, who beat cancer, has now had to beat depression, which she didn't have with cancer, and which she didn't have with ME, until she was blamed for her own illness and received absolutely no support, despite being much sicker than she was when hospitalized with cancer. She has developed anxiety problems, which she never had before. She is afraid of doctors, when she had such a happy relationship with all the cancer medical staff. She wants desperately to go to school, despite being told repeatedly that she must be academically unsuccessful, socially inept and lazy.

And she is so much sicker. I have seen her paralyzed with chemo, running high fevers, and almost cut in half after the major operation to remove her left kidney. I've seen her lose her waist-length beautiful hair, have to spend months away from her home, school and friends, and deal with so much stress through the cancer. I've seen her suffer before, and it's the hardest thing any parent can have to watch.

But I've never seen her beaten before. Cancer did not beat her. But ME has.

Yes, ME is a horrifying illness, causing continual terminal suffering for years and years. It's much worse than cancer and chemo.

But I still don't think it would have beaten her like this, destroyed her self-esteem, left her shivering in the dark, if she had been treated like a human being.

Suffering and bewildered, she was blamed for her own illness and treated with hostility by people who have sworn an oath "to do no harm".

My young daughter not only has to cope with the continual suffering and incapacity of ME, she has to cope with being disbelieved, taunted, insulted and marginalized. That's what has beaten her.

Name: Cilu

www.hfme.org

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[CBT is] not effective unless a person has underlying psychological issues with coping ineffectiveness, as with any other illness.

**Name:** SG  **Country:** Australia

I have been through CBT. For help with the physical effects of CFS, it has done absolutely nothing. What it does help with is how I mentally cope with how I physically am. It's also helped my depression, in combination with a SSRI. I had depression long before I had CFS, so I suspect that makes it a different situation than many.

**Name:** Johnno  **Country:** Australia

I allowed myself to be referred to and treated by the psychiatric lobby for three years, their diagnosis being post traumatic stress disorder, despite the absence of any specific trauma-worthy inducing factors in my life.

Consultations with psychiatrists turned regularly into discussions about my medication, usually SSRI's and the fact that they failed to address my symptoms at any dose, indeed often making me feel worse, in fact over-prescription causing serotonin syndrome at one stage.

Physiological symptoms were on the whole overlooked or interpreted as somatic manifestations of a psychiatric problem.

In utter frustration I eventually tracked down a professor who runs a ptst clinic for Vietnam veterans, and after a six week appraisal period with him he came up with the opinion that I had been misdiagnosed, this was not ptst, as he worked with it every day, and that my problem was physiological and probably neurological rather than the domain of psychology, there being no signs of psychiatric illness present.

So with three years wasted, and having been subjected to drugs which only seemed to inflame my condition I approached an ME/CFS specialist who tests and treats specific symptoms in line with clinical research findings that ME is a neurological disease.

After only a few months, various tests are proving typical ME abnormalities to be present in blood, neurological and endocrine systems, and have been given appropriate treatment.

Already we have mapped Insulin dysregulation; channelopathy problems; adrenal dysregulation; orthostatic intolerance; neurotransmitter dysfunction; and disregulated diurnal sleep patterns.

Bloods continue to show 5 times the normal levels of white cells, showing that the system is trying to fight off a pathogen, whilst a radioactive white cell scan showed no centre of infection, also red cells exhibit the typical clumping reported in clinical research, causing an extremely slow ESR, and blood too thick to negotiate the narrow capillaries of the innermost areas of the brain.

As a result of this scientifically based treatment I have improved dramatically, my most troubling symptoms are under control, and my physician is building up a picture of the systems which are not working in a balanced way.

I gave the psychiatric lobby the opportunity and co-operated for three years during which time I only got worse, and can only endorse from an experiential position the importance of scientific intervention by an informed physician, familiar with the idiosyncratic presentation of ME/CFS.

Dr Shepherd, in many ways the object of this post is to refute the efficacy of the psychiatric-based treatments which you and your co-horts endorse. Three years of CBT and monthly psychiatric consultation failed to address any of my symptoms at all whereas purely scientific medicine has in three months improved my functioning hugely.

My heart goes out to you all in the UK who are being prevented from accessing such vital yet simple intervention, and I support you in fighting the untruths and misinformation which prevents the severely ill from accessing appropriate treatment.

**Name:** A.H. Fife  **Country:** UK *(from letters to RiME)*
Before March 1994 I was fit and healthy and employed as a Head of Year and PE / Maths teacher who led a full and active sports life. On 8th March 1994 I suffered a strange debilitating virus which eventually became so bad I was unable to work, (incidentally, there was a cluster of cases of M.E, affecting to varying degrees, a number of pupils at the school.) The NHS solution was that nothing could be done but it probably go within two years, which I refused to accept and set out to find the solutions privately.

During the following three years I deteriorated until in 1997 I was reduced to crawling to the toilet, being carried downstairs and spending the day lying as still as possible due to severe agonizing headaches. In addition I suffered from terrible weakness, muscle aches, severe dizziness, blurred vision, sore throats, sweating and shivering, swollen glands, highly light and noise sensitive and digestive problems. I was barely able to sit up to eat, unable to watch TV or even converse for more than about 5 minutes,...

Every day, seems like eternity, spent enduring pain, feeling so ill, like your blood has been poisoned, with the frustration of being trapped inside a useless body, unable to concentrate and needing assistance to do the most basic tasks. For a couple of months I suffered the humiliation of being unable to feed myself. Whilst I am able to do this now I still need help to get to the toilet, to wash and dress etc. it is like the seasickness adage. First you feel so ill that you are afraid you're going to die and then it gets worse and you are afraid you are not going to die. I and most other sufferers, adopt a determined, positive and proactive attitude, which no doubt contributed to ME in the first place. Merely surviving these eight years of hell has been a far greater achievement than any of my academic qualifications, sporting achievements or job promotions.

Over eight years I have spent thousands of pounds, in vain, seeking a solution from many sources including ME Consultants, Acupuncture, Osteopathy, Homeopathy, Herbal medicine, Nutritional therapy, Kinesiology, Hypnotherapy, various healers, very many nutritional supplements. Immunogiobin, B12 and magnesium injections with little or no help from the NHS.

Governments, researchers and fundraisers need to realize that it's not just about saving lives but quality of life and that with severe ME this is zero. Society would not let animals go through such suffering and incapacity but ME sufferers are left to exist in a “living death” state for years sustained only by the distant ray of hope of recovery and a positive attitude that keeps you fighting and thinking that it's got to get better soon even after 8 years of disappointments.

Insult is added to injury by the fact that some people still believe a bit of graded exercise and some positive thinking is all that stops sufferers getting well. I used these methods to recover from an accident when I received 25% bums but with ME this results in deterioration rather than increasing my capacity. If only that was the answer I'd never be in this hell I'd have been well years ago enjoying a wonderful life that I had before ME.

It is a disgrace that there is no government funding research into aetiology of ME, (the only funding is provided through charities and donations, for an illness, which affects an increasing number of people of all ages) I urge you to ensure that this criminal neglect is ended now with desperately needed funded research into Neurology, Immunology, and other areas of dysfunction Severely affected sufferers must be included in any study, not just those well enough to attend the trials.

Name: N.B. Country: UK (from letters to RiME)

When first ill, after two and a half years in bed, I spent six and a half months in a psychiatric ward - the only help they offered on the NHS, I did graduated exercise and CBT, It did not cure me, I am still badly disabled with ME after 12 years and use a wheelchair,

Name: S.M. Country: UK (from letters to RiME)

Over 13 years ago my brother contracted an unknown illness rendering him bed bound and hospitalised at the age of 18. In hospital he underwent tests and was put on a program of graded exercise which left him flat out, bedridden, hardly able to speak or feed himself and unbelievably in the geriatric ward, a totally unsatisfactory and inhumane treatment,

My parents took him out of hospital and have cared for him at home, trying to understand this illness. Until 18 months ago he had made progress and had reached a level where for short periods of time he could watch TV, use the Internet and get around the house in a motorised wheelchair. But after trying to get better to everyone's disbelief he deteriorated to a condition even worse than before.

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He is now lying in bed in a darkened room, again unable to stand light and sound, unable to sit up in bed or even roll over. He can only move his forearms and speak for extremely short periods of time. He is being cared for, spoon fed and toileted by my parents and has absolutely no quality of life. This leaves my parents with a life of hard work and stress beyond belief and no rest.

I believe the only way forward with this illness is for the medical research council to fund proper research as stated on the petition. Everyone is entitled to some quality of life.

Name: J.S. Country: UK (from letters to RiME)

Severe ME is not cured by cognitive behavioural therapy anymore than a severe type 1 diabetic would be, who is in need of insulin.

Name: R.I. Country: UK (from letters to RiME)

The exclusion clause, "... but with the exception of psychiatry ." in your petition, appealing for a co-ordinated research programme into the aetiology (underlying causes) of ME. begs the question why psychiatrists should be involved in the treatment of people with M E , unless they have a history of, or a concomitant, psychiatric illness. It is understandable that people with M.E. are fed up with the loss of career (or interruption of education in children), reduced standard of living, social isolation and fractured relationships, sometimes compounded by disbelief & derision, on top of the discomfort of the illness, but this is not the same experience as clinical depression, which is not thus explicable. Of course, some people with M.E. may have depression, or some other psychiatric illness, but the one is not a prerequisite for the other.

Since M.E is classified as a neurological, not a psychiatric or mental illness, it may, at first, appear hard to see why psychiatry has taken such a dominant role in research and treatment.

Chronic Fatigue Syndrome is an umbrella term, under which a number of illnesses, in which chronic fatigue is but one symptom, are contained, ME is much more than mere tiredness The terms are not interchangeable as putting a / between them suggests.

Since we are not talking about the same illness, there ought to be different research strategies and the treatments suggested by findings as suitable for one condition, for example graded exercise or cognitive behavioural therapy, may not be suitable may even be harmful - for the other.

Many of us think CFS needs to be "unpacked" redefined, or abandoned altogether. Thanks for your initiative, in particular on behalf of those who are so severely affected that they remain isolated, invisible, without a voice.

Name: P.L. Country: UK (from letters to RiME)

As a social worker, I have met several people with this illness, I was very surprised to hear that the Government is funding no research into its underlying physical causes.

In addition to the human suffering there is the question of cost. ME currently costs the country over £4 Billion pounds per year The state has a duty to investigate. What is behind this much misunderstood illness and enable people to improve / recover so they can resume a useful role in society.

The small sums of money which up to now have been spent on psychiatric models of treatment are not working and are inappropriate.

Name: M.S. Country: UK (from letters to RiME)

When I contracted ME, I was a young student. Doctors were unable to diagnose or treat the illness but they maintained a professional interest, gave me (the patient) the benefit of the doubt, and were interested in learning more about ME.
The power and influence of the psychiatric lobby changed all this. In recent times, I have either been treated as a psychiatric case who needs to be humoured or a difficult case that does not fit into any medical category and which can be ignored. I have been put on Graded exercise and CBT Programs which have led to a deterioration in my health.

Psychiatric bias and manipulation of the facts has adversely affected the way that I and others are treated by GP's, Consultants, employers and family, even.

Name: Joy Birdsey  Country: UK

My name is Joy, I am a psychologist with ME since 1995. I was invited to go to CBT by Medway health authority. Personally I did not want to attend, as I knew how ill I would feel the next day and knew that CBT could not cure a biological illness. However, I decided that I should go keep my mouth shut and observe and participate, so that when the time came and I was asked "How was CBT" "what do you think of CBT" I could answer honestly.

The room in Medway Maritime Hospital was sad to say the least, chairs that had seen better days and it was almost like a corridor made into a room. There were approximately 20 of us for group CBT. Run by a leader, a nurse, and a psychotherapist. Now if you know anything about cognitive behavioural therapy, you will know it is personal and should be client centred, groups do not work. I can explain why, but it will take too long and I have only a very limited amount of energy.

First question by the leader "what would you like to get out of these sessions?" that was the sad part for me listening as many said to get better. We had the handouts of filling in forms (if they knew anything about ME the last thing we want to do is fill in a form of what we do from day to day. Then the next week our goals and aspirations and so on.

With that how are we going to exercise? Answer add 10% on your daily walking. My reply to this was "Surely if I walk 10% extra every day for a year I would circumnavigate the world. My remark was not taken with amusement.

Well all this rubbish continued for a year, approx every month. and the group dwindled down to 5. There was, no input from nurse or psyio, when I had a chance to ask the psyio what would be the best for my pain, the answer was, we cannot do anything for your pain!

After the year we were called back 6 months later, it was good to see my 5 fellow ME sufferers, but the look on their faces when all we had been called back for was to be told well that's all folks, and now will you tell us how well you have done having all this CBT. GROANS! and disbelief from the group, "you will not be following us up at a later date?" then one asked "no thats it" I said do you know not one of us has seen a consultant, except for psychiatrists. Silence no reply was the answer.

I had a word with my GP and I said "you know this CBT is all a load of rubbish? Don't you?" his reply was "I know"

CBT is a load of flip charts and forms. It took me over a week to get over CBT each time I went. The only good thing about going to the hospital was making friends. However it made me so aware of people who were to ill to attend and suffering social isolation and the stigma of a psychosomatic illness. I am now virtually wheelchair bound, but I do have days of clarity and when they come I try to make people aware, well any one who will listen.

You have done a really good job with this site. Please forgive errors in this mail I just have not got the energy to correct it.

Name: Naomi  Country: United Kingdom [Online]

My name is Naomi, I'm a twenty year old woman from south England. I became ill when I was fourteen years old, in the middle of secondary education at a school of high standards. As I fought for diagnosis, struggling to keep up with classes and appointments, the school became very impatient. After infinite testing and stress I finally got a diagnosis of chronic fatigue syndrome, when I was sixteen, just after my G.C.S.E.'s. With my newly issued
doctors certificates I was determined to prove to my teachers that I was not just lazy as they had suggested, so I decided to stay at school to study for A-levels. The school didn't become any more cooperative and made things very difficult, but despite having to miss much of the courses I was taking, I passed my A-levels and left the school.

I am currently too ill to pursue a career of any description. becoming ill so young has meant that I have never had a real job. I do have supportive friends and family though and I'm very happy with my lovely understanding fiance. I live with my fiance, our two dogs and two cats. My interests include art, films, music, cars, pets, poetry, sports, tv, science, psychology, television, good conversation and anything funny. Before I became ill I was a fun loving, social person who would try anything once. Now I'm a little more conservative, but still love a laugh.

Name: Tritt
Country: US

CBT only helps deal with profound loss – grieving. CBT is NOT a CURE for PTSD, panic attacks, OCD, DEPRESSION, nor CFIDS or FM, ALL of WHICH ARE MEDICAL PROBLEMS. CBT just helps deal with re-establishing human value (despite imperfections of chronic disease processes) & choosing more realistic expectations. 6+ years of CBT only helped to heal and grieve from profound losses (I came down with CFIDS & lost ME & my career, home, marriage, car, etc.). But then 12 STEP Programs were even more helpful. Living the 12 STEPS are having a ‘framework’ for grieving & dealing with disappointments & loss plus, like CBT helps to derive a “HOW TO” live as functionally as possible! And with NMH - blood pressure disorder that gives symptoms of PTSD, treating the medical issue is imperative! CBT only helps to realize you can choose NOT to GO TO ADRENALINE most of the time (unless you get a shock)! Insurance Companies have a LOT of $$$ invested in getting people misdiagnosed with ‘mental illness’ so they have 2 yr limit on LTD, so they won't allow medical information to be publicized, and the pharmaceuticals are making BILLIONS by TREATING SYMPTOMS only! BEWARE!!!

Name: Flora
Country: UK

I am Flora, mum of Samantha aged almost 16 and poorly on and off since aged 6. It’s been horrendous with doctors saying, ‘pull yourself together’ ‘low pain threshold’ ‘school phobia’ etc. Sam was eventually diagnosed 2 years ago and has been out of school almost 4 years. She was severely affected, still is, but at beginning of 2003 she was seen by a psychiatrist. We had no choice but to see her ..we needed some help. Fortunately the young girl was nice and not one for “pushing” depression or psychiatric issues.

She did advise CBT however and we took Sam. Firstly ..they don’t have a clue and arranged her appointments early in the morning.. we had a 15 mile each way drive. 1st visit we all saw two therapists. We were asked family history etc and really made to feel it was in some way our fault. 2nd visit Sam saw therapist alone. She talked about Sams thoughts and views on various things and according to Sam made her feel about 5 years of age.

3rd and final time ..after then not being willing to give later appointments Sam came home in tears. She had been asked to draw her picture of different feelings she had..happy,sad…angry etc. She was then asked questions like” if the neighbours dog did a toilet on your path who would you get to clean it?? How would you feel and what would you do about it?"

This was the final straw and we never went back. Samantha's words were " I feel so belittled mum".

GET: We had a physio come to the house at the same time as above. She wanted to get Sam walking 50 yards ASAP. Her first method was to have Sam on her knees in our front room picking up sweets off a plate with her mouth. Needless to say we stopped that rubbish too. Sam can now manage a visit to a shop in wheelchair occasionally and isn’t bedbound (even if almost housebound). [CBT and GET are] useless, stupid and WRONG, that’s our opinion.

Name: MONIQUE BRENNAN
Country: UK

Firstly, I had never heard of such an illness when I frist became ill in July 2004. In fact, I rarely became physically ill and so such illnesses were of little interest to me being a healthy person and busy finctioning at a full capacity. I remember the morning well. I had, had a bad nights sleep and had been having night sweats for a few weeks, so bad that I had to get up in the night to change my clothes and bedding. This particular morning I felt as though I had been fighting off a flu or something, it was winter and I had, had my flu injection but being around a lot of students I thought I may have caught something. My throat was very sore, I had bad stomach pains and I felt

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giddy, foggy in the brain and generally unwell. I was do to do my counselling exam that morning which was a practical exam. I had always done well in exams and particularly exams I had to talk in so I was not particularly worried. During my exam I could not think, could not function and I realised I felt really unwell and had to defer. I thought I would be better in days, but over the course of the next 10 days I became incredibly worse. It was as if I was drugged, every limb and bone ached in my body, my glands were inflamed and hurt, I could not tolerate light, sound. My limbs spasm and I could not rise from the sofa for 10 days until my partner decided this virus was going on too long and got me to a doctors. By this stage I could hardly walk, my left side in particular my leg was not coordinated, muscles extremely weak and I truly felt as if I was dying. I had gained 20 kilo's in fluid that made my once thin face look like a frog and my left leg extremely swollen. 

Bad virus the doc told me, keep taking meds it will sort itself out. Went to 3 more docs same thing, wait it will go. Well it didn’t go, in fact it got worse, now I was almost bedridden and had to pace out activities and sleep inbetween. 3 months later Doc said chronic fatigue syndrome, stay on meds, you must begin graded exercise program, take anti-depressant, eat well and you will get well oh and lose weight she said.

Mind you I was 60 kilo's before illness and suddenly ballooned to 83 kilo's never had been so heavy in my life and it was a puffy heavy with swollen belly that reacted to everything I ate. So began to push myself with walking stick 5 mins a day walk, some days o.k., some days too sick and in pain to walk again for several days. Took 6 months to push myself to 25 mins a day with no improvement in health or fitness level as compared to years previously where I actually worked as a fitness instructor and I knew something was not feeling right here. I was becoming weaker instead of stronger, inflammation was increasing, breathing problems increased, swelling on left side increased to noticeable and frightening amount. All in all this was not working and I was putting 100 percent into it. Doc just looked bored, ‘keep exercising.’

Talked to psychologist I had seen for trauma. CBT, I knew CBT like the back of my hand I had been learning it for 8 years. She spoke of CFS as if it were a psychological disorder, I felt very perplexed, I had studied Psychology long enough to know this was not in my head, it was in my body. No amount of CBT logs worked for this. It is not your thoughts that need reprogramming, it is your body that needs healing and it is other peoples thoughts that need reprogramming in understanding that anyone this alone, this ill, this scared, this disabled is going to be suffering depression and anxiety in due course from no one addressing their actual needs. 12 months has passed, no one has helped. Today I got a referral to _______ hospital to a doc who supposedly treats ME/CFS. I think its very sad I was left for 12 months in such pain, disability and fear with a 12 year old to care for, before anyone actually acknowledged something is very wrong.

**Name:** Luke* **Country:** UK

In the early days of being ill (when it was originally thought that I was suffering from acute stress), I was advised by my GP to take longer and longer walks each day. This I faithfully did, until one day my legs gave way suddenly and completely, pitching me onto the roadside.

Fortunately, living "in the sticks", with rarely a car passing by on the tiny backroads, I wasn't involved in an accident. It took a good fifteen minutes or so for enough strength to return for me to be able to stumble to the nearby post office, where I was immediately offered a chair and a glass of water. It was a further twenty minutes or more before I was able to struggle home.

This event turned out to be a landmark in the further downturn of my condition.

I was also offered half a dozen sessions of counselling on the NHS, during which the counsellor (bless ‘im) attempted to teach me to juggle. Although I approached the task with dogged determination, I was completely unable to learn, because of marked loss of coordination, bad balance, lack of muscle strength, difficulty with concentration and visual disturbances (not to mention the blinding headaches etc.) and rapid exhaustion, which, of course, all made me feel even worse physically, not better.

With hindsight, I realise that both these attempted activities were beyond my capabilities at that time, and may actually have done me long-term harm. I clearly allowed myself to be pushed too far, and that, I am sure, was ironically because of my usual determination to solve problems, overcome obstacles and do a job properly.

Nowadays, although I still have a similar determined approach to life, it is no longer "terrier-like", but gently persistent - and realistic. My concern about approaches to treatment for M.E. such as CBT is that patients are
"persuaded", against their better judgment and experience, to attempt far more than they are actually physically capable of, being made to feel that they have the "wrong" attitude of mind.

As a result of following a course of CBT years ago (although it helped me psychologically to cope with being ill), I tried persistently to not use my walking stick for some time. Again, with hindsight, this made my walking problems worse.

I can't blame anyone for what happened to me in the early days, to be honest, because these "treatments" may well be very appropriate for, and beneficial to, someone suffering from stress, anxiety, depression etc. But they clearly weren't appropriate for someone in my condition.

**Name:** Suzy [from Invest in ME]

'A nasty deterioration started to set in quickly. Apart from other worsening problems that Suzy began to experience, she found herself needing to lie down for most of the day since any activity, physical or mental, was becoming impossible.

Less than a year on from the start of this bad deterioration, the illness turned into a nightmare of the worst kind.

The months dragged by. For the first two years they saw Suzanne deteriorating in her bed-bound existence, often unable to communicate (let alone hold a spoon) even by blinking or finger movement.

By the time 8 months had passed Suzanne could only manage to wake up for about 2 or 3 ten minute periods-----if we were lucky ----- out of each of the two separate hours in the day we chose to try and wake her. In order for this to happen Mum or Dad had to spend 3 hours sitting quite still and silent in the cold dark beside her bed.

Eventually (making it sound much simpler than the choice actually was) we decided to reduce this procedure to just once a day instead of twice, and to aim for one hour of time awake for Suzy between 7 and 8 in the evenings.

As before, Suzy would only wake up after Mum or Dad had sat beside her bed for 3 hours gently trying, very occasionally, to coax her out of her comatose state.

We gradually reduced this 3 hour period, but it took over 18 months (until around June 2004) of painfully slow improvement in Suzy's state, for us to dispense with it altogether.

Suzy's motivation for waking had always been that she was desperate to try to eat (even though this wasn't always possible), as she was so fearful of being tube fed as we were told must be the case-----just as she begged us not to let her be hospitalised, as this was also something we were facing.

(It's only by understanding gained from living with this condition that our desperation to keep our daughter at home could be understood.)

Suzy was in a "living death" state for the first two years after her illness became really severe. Many would still regard her as such since her condition remains very sad.

Even up to around October 2004, two people in the room or one person stringing more than three sentences together was too much for her. Thankfully, things in this respect have now improved. Though the two people are still mostly restricted to Mum and Dad, wonderful exceptions have begun to happen recently for 10 - 15 minutes later in the day.

Suzy's life was, and still is (except for her fans no longer being continually on), spent in a perpetually darkened, unheated, noise-free room. There are blankets over the curtains------despite it being a north facing room; bedside fans are periodically on------even though she only wears thin short-sleeved T-shirts all year round and; ear plugs in------even though the room is in a very quiet location). (…)

There is a positive movement------albeit inconsistent------undoubtedly happening in Suzy's condition. In fact recently it is happening relatively quickly. We are just so frightened of when and where it might stop.

We feel this improvement has emerged because of our developing confidence in being able to reject [psychiatrically based] medical approaches to Suzy's severe ME, and to the departures we chose to make from these treatments. (…)

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2. We were certain that the graded exercise program Suzy followed in the early stages of her ME was a big mistake. We had no hesitation in no longer sticking to any kind of graded exercise routine. Instead we took the approach of letting Suzy do what she felt she could do—-which for nearly two years was nothing at all. This is a second option we are convinced we made the right choice over.

3. Stopping the involvement of psychologists
A third decision we know to have been the right decision, was to stop the involvement of psychologists in an illness we are convinced is not psychological.’

Name: Ken Country: Australia

There is good CBT and bad CBT. The critical difference between the two is the issue is control. In spite of what many esteemed professionals think, most PWC’s know their condition better than anyone else. Most tend to overestimate their capacity. CBT or GET that pushes a PWC is likely to fail, through relapse, withdrawal or refusal. Sensitive, responsive therapy may help, but lets be realistic here. Any gains made are likely to be modest at best - if you doubt it, look at the research.

Scientists get excited about "statistical significance", but the actual size of this difference is always small, if it is found at all.

Name: Emma [from Invest in ME]

‘This was the second paediatrician I had spoken to, the first wanted to repeat all the blood tests from a few weeks before, and was suggesting anti-depressants and a hospital stay before he'd even seen her. Emma was now so noise sensitive that I couldn't listen to the radio at home and the thrice-daily playtime at the nearby school would reduce her to tears. She was also very light sensitive and had the curtains permanently drawn. Bright lights or sunshine made her weep with pain. Hospital would be agonising.

We borrowed a wheelchair from the Red Cross, bless them, to get to appointments, and to escape from the flat we went out using my new toy, a bat detector. Fortunately there was a roost just up the road that was accessible by wheelchair and bats like it quiet and dark too.

Some time around May or June 2003 I got a letter from social services asking me to contact them. In my innocence I thought it was a follow up to our claim for DLA (Disability Living Allowance), so from the disability team offering support. Not a bit of it, my sister had reported me for suspected Munchausen's by Proxy. The fact that she hadn't seen us for two years hadn't held her back. So to add to the difficulties of dealing with the school, the benefits system, a paediatrician from hell and a sick child, I now had to deal with a social services investigation. Fortunately, I laughed it off and suggested they check their files - we'd been there before when I wouldn't play ball with my dysfunctional family and that social worker had decided that I deserved sympathy: she found my family overbearing. I heard no more about the investigation, just silence. But it meant that I felt as if I couldn't contact Social Services for support in case I reopened that particular can of worms.

We also had a visit from the medical examiner from DLA. I'd read such horror stories of DLA being turned down that I pushed Emma to overdo it the day before so he could see how ill she really was. It was a mistake. She was back to having full body spasms, having to be held down on the bed so that she didn't involuntarily flick herself off on to the floor. It also took weeks to recover.

Another little humiliation was the monthly visit from the Educational Welfare Officer. He was pleasant enough, but the permanent checking up by officialdom was not. It also used energy better spent constructively.

This isn't all doom and gloom. Now, in April 2005, my daughter is much better and is doing her best to "pass as normal" at college. She's attending part time, taking 3 AS levels to add to the 5 GCSEs she passed well last summer. It has taken all this time inching forward to get this far, including over a year using a wheelchair. We passed on the GET (graded exercise therapy) and CBT (cognitive behaviour therapy), which was all that was on offer and relied on pacing and diet as treatment - going it alone.’

Name: Teresa Foley, PsyD

I am a doctor of psychology, and never did like cbt but it is being used because there is [sometimes] a short term gain which is mislabeled as success. Then another symptom appears and cbt is used again. It is short term and the
insurance companies like it. The insurance companies and the drug companies decide what "works"; despite the research to the contrary, they continue to pay for cbt but not psychodynamic approaches, which I feel are most beneficial. When someone has this illness, it helps to be listened to, and heard, and then to check in and repeat what was said in a different statement to check and see if the therapist is following the client.

I cannot see how beneficial it is to blame to patient as in: what are your thought forms/schemas and what is the antecedent that led to your disorder, and then finally the solution. NOPE. It nicely puts a ribbon on a difficult situation and blames the patient in the process. As if the thought forms caused the "problem". I believe we create our reality in relationship to other people and outside influences.That is why cbt is so narrow and in the end does not work. If the therapist instead met the client at the point of reality that is the client's reality and followed from there, it empowers the client, educates the therapist, and a new reality comes bursting from this interaction providing there is sufficient therapeutic alliance.

I have had ME/CFIDS for several years. Over that period, there have been several therapists who did their best at getting me into "a happy mood, strategies for living, and the original story/or theme that caused the depression. antecedent, behavior, and response." The idea that I had several ways to interpret my "condition" was pejorative at the least. It is v easy to be a therapist who has never been taught to be with those who have chronic illness. Just be with the person, not try to fix it. It isn't fixable, but resources are welcome.

A Personal Story- Sheila Barry [Online]

‘You will have heard, or you will hear, from people who are very qualified to speak here - I regard myself as an ordinary mother but then nothing is ordinary if you have an ME sufferer in the family. So why have I travelled down from York to speak at this book launch. I am here to tell you of the devastating effect the situation outlined in this book, has on the lives of ME sufferers.

Skewed clearly outlines the reasons why many of those suffering from ME feel alone, isolated and have little hope for the future.

I personally regard psychiatry as a growth industry. The number of conditions identified as mental illness has grown tremendously in recent years. MS and Parkinson's, among others, were earlier identified as psychiatric illnesses and recently I read that 'shyness' has been classified as a psychiatric condition. How do they arrive at these decisions.

Psychiatrists classify a condition when a number of them are able to agree a criteria. They have no diagnostic tests. It is simply a matter of opinion.

I believe that the actions of the psychiatric lobby to have ME classified as a psychiatric illness and to prevent research into the cause, and a diagnostic test were the major reason that my daughter chose to end her life.’

Frank Albrecht franka@skipjack.bluecrab.org [Online]

‘I don't think any PWC should go to a CBT practitioner who thinks CFS is an emotional condition, or that it is not, clearly, a physical illness.’

Name: Hazel Griffiths

My experience of CBT was quite a positive one. Surprisingly, in fact, since the whole thing got off to a terrible start with the woman who assessed me; I found her incredibly patronising and closed-minded and felt she had a fixed idea of what she would find before I even set foot through the door. I had "somatisised" my symptoms i.e. I imagined they were physical but actually they were psychological. I very nearly refused the course of ten CBT sessions I was offered, but, like many of us, I was desperate and would’ve tried just about anything.

The woman therapist, however, was very different. From the outset, when I told her my views of being labelled as having a psychological illness, she told me that she knew very little about ME (not reassuring for some people, I know, but I was very happy to hear this as I felt she would have an open mind and listen to me) and that her job was to find ways of making life easier for the patients she saw who came to her with a range of chronic conditions. In fact, I don’t think she treated me any differently than a Multiple Sclerosis patient, for example. Her
view was that any chronic condition caused a wide range of problems for the sufferer, some physical, some mental and some emotional and that she would work with me to find possible ways of reducing any of these.

At the beginning of the course of treatment I kept a "diary" to help identify my patterns. This didn't really tell me a lot that I didn’t know already, but did make me realise that I had quite a sound strategy for dealing with things rather than just the muddling through that I’d always thought I’d done. Also I had worried that I seemed sometimes to be able to "push through" [symptoms] by making myself do things, but the diary showed that I almost always paid for this later (often a couple of days later.) One of the best things about the sessions, though, was that it dealt with the anxiety I had that I was somehow making things worse for myself, or that if I could just "do it right" I’d get better.

Finally I came to realise that it was okay to find living with ME difficult and to get angry and miserable and that I was actually coping reasonably well under very difficult circumstances.

A friend of mine who is a clinical psychologist tells me that the way CBT is applied, and the quality of therapists, varies a great deal. [A big] problem seems to be the expectation of what CBT can do. CBT cannot cure ME, or even improve symptoms; what it should be able to do though is make coping with this horrible illness a little easier.

Name: Kel

Have just finished a course of CBT with Occupational Therapists at Wareham Hospital, Dorset. Six, three hour group sessions over eight weeks (6 or 7 people in my group). It has not been suggested that the techniques we've been given constitute a cure. Merely that they will make it easier to cope with the illness and put us in the optimum position for recovery. I've been diagnosed very quickly, so theoretically I'm in a good position to make a recovery.

Name: Fox

It seems to help a little bit for your emotional well-being, but it doesn't help to get rid of even one of the many physical symptoms of ME-CFIDS-CFS

Name: Erik* Country: Switzerland

I am writing in behalf of my son (16), ill since december 2003 (almost 18 months now), just got a week ago a diagnosis from a brave pediatrician, not yet acquainted very much with ME/CFS and ready to read through all this documentations (canadian guidelines, etc. etc.). My son still being in danger of being harassed by schooldirector and child protection authorities and psychiatric clinic.

Was recommended a GET and behavioural therapy by the chief of a departement of children hospital. My son is homebound ever since he got november last a yeast treatment from a doctor (Perenterol), as of his most serious additional belly problems.

He does not think at all that this form of therapy will help him at all, as he sees already without this how little it takes to overexert himself (eg. the visit at home of a kind doctor), he does suffer serious post exertional malaise and eating is getting always a problem.

I am writing you from Switzerland, where just a short time ago a professor published in the swiss medical weekly an article saying that cfs/me is a psychiatric disorder and closely relied to fear traumata, fear denial, depression and other crap.

I do know after seeing the condition and the changes therein for such a long time now and after running from doctor to doctor first, that the medical personal are to a big extent a very strange kind. (I am really so sorry to say!)

My son would state here that you also could treat a broken leg with psychiatry if you would not know better. And that never a doctor would get the idea to send somebody with a broken leg on a marathon; something which seems to him would be a good comparision of what was asked of him sometimes! He just was not taken serious till we
were lucky to find this pediatrician now. And what my son does not know, the authorities are still seeming to go on... I really hope they will understand!!!

Name: 3times* [Online]

[CFS] is not in our head so, in my opinion, changing one's behaviour is like washing your car when your engine has a mechanical problem; It makes you feel good but it does not fix the problem at all.

I admit therapy can help you with self-confidence, relationships and such things but it does not mend broken bones or does not cure cancer no more than it can cure CFS. And it can even add to the frustration to have one more professional tell you it must be in your head - in other word you are causing the [CFS]...

The money spent for years of therapy is about the same as the price of a brand new car...Neither is a cure for CFS, but I think the car would have been a better choice for me :-)

Name: mrlj*[Online]

I had been in therapy for three years when CFIDS was diagnosed. CBT was great for other living situations, but was about as useful for CFIDS as insulin for a broken bone. The treatment needs to fit the disease.

Name: karinya [Online]

I undertook Cognitive Behaviour Therapy soon after I was diagnosed and it was extremely beneficial in those early stages of coming to terms with all the implications of the diagnosis. I was extremely lucky to fluke a therapist whose sister also suffered from CFS, so my therapist was very much in tune with CFS and its effects, which made a big difference I think. CBT is also very beneficial for life in general and I am very glad I did it. Some of the good habits established wear off a bit in time, so it is probably a good idea to do a couple of refresher sessions occasionally also. It won't cure your CFS but it will help enormously with your ability to cope and to make the best of where you're at.

Name: B.H. Country: UK (from letters to RiME)

This treatment [CBT] has been the only one offered by our GP and was not successful. Subsequently our GP practice has largely ignored us.

Name: Annabel* Country: Australia

[On a recent trip to hospital and what the ‘psychiatric approach’ can mean for M.E. sufferers]

Being in the hospital was an absolute *disaster*, with everybody there thinking I was making it up, somatizing, etc. They set the psych team on me. They refused to feed or wash me, saying that if I really *wanted* food or to be clean that I would magically recover sufficiently to manage these things myself.

At one point, a gang of about six of them came in and announced I was going to sit up. When I pointed out that it made my heart rate and blood pressure go cuckoo, they pointed out their opinion was that lying down *caused* these diseases (which I know to be false). So I was forcibly sat up against my will, and then they left me with the head of the bed vertically up and no way to lie down or move, with no nurse's bell or way to call for help, while I was dry retching and crying and dizzy and begging them to let me lie down.

They did that twice, that I recall, leaving me there helplessly and obviously very ill until some random passer-by happened to take pity on my and put the bed flat down again!

They also frequently told me I needed more "light and air and socialization" and to this end, they moved me from the nice quiet single room I had been put in to a 4-bed ward which was the noisiest I have ever been in, with bright sun and no curtains, and then objected violently to my very necessary eye-shade and earplugs.
I had been warned this hospital had a weird attitude to CFS patients but I had no idea it could be THAT bad! I eventually gave up and couldn't take what I perceived as intentional torture anymore and begged them to let me go home, which they did yesterday.

So now I am home again, with no prospects for a future that I can see.

I am frightened.

After discussion with the advocate my current plan is to go and see a reputable CFS-specializing doctor who I have wanted to see for ages anyway. He should be able to provide me (yet again) with a bunch of tests that show *physical* evidence of my disabilities and hopefully this will help my advocate to get better treatment for me - she thinks it will, anyway.

Only catch: The INITIAL two visits to the doctor total $500 which must be paid $300 at the initial visit and $200 at the second visit, and the total medicare rebate across both comes to only $150.

[This occurred in May 2005, Annabel tells me that this abusive hospital trip caused her already very severe condition to worsen considerably. It is now one year and 3 months after this event, and she has still not physically recovered from this hospital visit even slightly and she remains as ill now as she was when she first left, if not worse in many ways.]

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Surveys on people with M.E. on CBT and GET:

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

**Results of survey:**
Graded exercise therapy: 95% found it unhelpful
Cognitive behavioural therapy: 93% found it unhelpful

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**SOME FACTS AND FIGURES ON CBT, GET AND OTHER APPROACHES Directly from the 'Horses' Mouths:** written 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. The aim was to find out what really worked in treating these conditions and based on findings, to then compile Guidelines on Diagnosis and Treatment for Clinicians and other Health Care Professionals.

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

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. One thing is certain: psychiatrists have made things worse for many, in more ways than one.
Comments from Greg Crowhurst of the 25% M.E. Group to the Gibson Enquiry; December 2005

Includes comments from 25% members on CBT, GET and the effect of the ‘psychiatric’ approach to M.E.,

“This will be revealed as one of the biggest medical scandals in history” declared a severe ME sufferer. This Report, based on an email survey of sixty-four severely ill, classical, Ramsay-defined ME/CFS sufferers, with a “multiplicity of symptoms” including, muscle phenomena, circulatory impairment and cerebral dysfunction (Ramsay 1988), was conducted at short notice in December 2005 especially for the Parliamentary Inquiry, by the 25% Severe ME Group.

"It is bad having severe ME but not as bad as being treated as a time wasting malingerer by the medical profession and the Department of Works and Pensions", remarked one respondent.

A respondent describes how “This illness makes life hard enough as it is. It is so much worse that, whilst there is the ability to investigate this illness, that opportunity is being deliberately ignored. The choice the medical profession is making to treat a physical illness with psycho-nonsense is never going to cure anybody.”

Another sufferer sums up the situation: “If the psychiatrists continue to influence research and funding into ME we will never receive appropriate treatment or recognition for the severity of the illness. The many biomedical discoveries into abnormalities in ME patients are ignored by psychiatrists who inform the world (including our GPs and all medical staff we come into contact with) that we are suffering from a somatisation disorder…If the government continues to be informed about ME by a wholly inappropriate sector of the medical profession then many thousands of severely ill people will continue to be seriously ill and not taken seriously.”

A sufferer recounts a typical experience: “I have been turned away by a neurologist, who did no tests, his comments were ‘you need to get out more’. I am severely affected and 80-70% bedbound, 90% housebound. I am desperate to be free of dreadful pain and illness, and go out and live my life. I cannot find the words to express how frustrating it is when the suggestion is that I am in bed ill out of choice. ….I have been told by an ex-friend that I might be attention seeking, and that if they don’t give me attention when I am ill, then that is best for me. I have even been told by a GP that if I meet someone and fall ‘in love’, I might find all my symptoms disappear”.

There were many other such horror stories:

- All nurses I have encountered, bar one whose daughter had ME, have treated me with contempt, lack of understanding and actual neglect during a hospital stay as they had “far worse off patients than you” to care for.

- Even now, after engaging in another battle with the local health authority because I was confronted with a doctor (previously) who would not even discuss a report with me which had been produced and provided by the ME Specialist I saw, I feel the new doctor, at times, is merely paying lip service to the fact I got put on his list via the local health authority rather than by his choice. This, lately, has caused him to develop an “attitude” with me and I keep biting my tongue when confronted with such an attitude. Not only is it appalling behaviour but I believe he is trying to see how far he can push me and then he can feel justified in saying to the local PCT he wants me to be removed from his surgery list.

- A hospital psychiatrist put in my notes that she suspected anorexia as I was very underweight - my inability to chew solid food due to muscle weakness and oesophageal spasms were classed as anxiety related. If they had been classed as the physical problems they were, I would have been put on a high protein liquid diet (or even been tube fed which would have been a Godsend) and given muscle relaxants to stop the spasms – both of which would have been invaluable. Once I was back home, my GP prescribed the muscle relaxants I needed (at my request) and I easily gained weight on store bought high protein shakes. Yet the anorexia notes are still in my hospital file and place a stigma on me which colours any future dealings with hospital medical staff, despite me proving that anorexia was not the issue – a physical difficulty was, and despite an earlier psychiatric report which stated I had no behavioural problems. No matter what evidence to the contrary, the psychiatric label prevails.

- I have been shut in an AIDS ward for 7 weeks and the staff have been told to “Limit Patient contact” and “Write down everything he says” despite being mentally sound, and never sectioned. This was in an Immunological ward. Astonishing that this should happen in the NHS after so much is known about M.E

- My GP’s practice seems to have the opinion that ME is nothing, and that it is related to depression, and that if you are in bed, then you have “given in”. When I have tried to explain to my GP how ill I feel, or
try to explain different symptoms, I feel I am not believed or that I am exaggerating…A family member asked me about my illness, and when I tried to explain what I was feeling, and how difficult it made my life, she dismissed every thing I said, and ended the conversation by saying that I “should be locked up. And that I was not fit to be out, and I should be locked in the Psychiatric unit immediately”

- My GP gave me a leaflet his practice had received from Simon Wessley’s unit at Kings College Hospital in London. I read it and said that the condition it described had no similarities to what I was experiencing. He suggested I go for an initial assessment anyway which I did – at great cost to my health. On arrival I was horrified to find that the ‘CFS’ unit was in the psychiatric department KCH and at that time, security doors protected it. I was also concerned that I was attending a ‘CFS’ unit since this label did not describe my complaint. It came as a shock to be seen by a psychiatrist who displayed little or no understanding of what I told him. My symptoms, most of which are included in the Canadian Criteria, were dismissed or ignored. At the end of the consultation he suggested a course of CBT and said I should take up exercise and get some hobbies. Six months later I was called for a course of CBT which I declined. The therapist became aggressive and defensive when I explained why.

Sufferers -- who are desperate for physical research and treatment -- are very aware of and extremely angry about the impact of the predominant psychiatric paradigm upon their life:

- It has destroyed my life. Now 22 years in severe ME state with no appropriate treatment for a neurological illness.

- ….terribly bad -- makes my situation twice as hard – now I have to deal with the illness and the negativity of the medical profession and media. I have been ignored by the medical profession on the whole, and at other times ridiculed and verbally abused. This has all caused me untold stress and suffering.

- It ruins lives. If you do not respond to CBT and Graded Activity you are given up on. The medical profession, and lay persons, think that ME is just pain and fatigue and we are all depressed, even in the face of evidence to the contrary. The only treatments offered aim to correct these symptoms, and any other symptoms are classed as psychosomatic. Because of this serious, debilitating and potentially life threatening symptoms are left untreated causing unnecessary suffering.

- I feel that I have to constantly explain myself. I think most people understand and believe I’ve got a real physical illness… but there’s still this idea that there may be a psychiatric component to it. I feel that if I had another more recognised neurological illness like MS I wouldn’t have to continually explain things.

- THEIR ATTITUDE HAS been an absolute bane on my health and well-being. I have had problems with doctors, benefits, and my permanent Health Insurance thanks to the psychiatrists’ attitude towards ME and appalling treatments suggested.

- Since contracting ME over 10 years ago I have experienced misunderstanding, neglect, rudeness, ridicule, ignorance and what can only be described as downright cruelty from almost every area of society (medical profession and some ME charities & their officials included).

Another sufferer describes how, despite an “extensive psychiatric evaluation” which resulted in a report saying ‘she is severely physically disabled’, ‘has no mood or behavioural problems’ and ‘is coping remarkably well given very difficult circumstances’, she was still offered “CBT and counselling and my symptoms of severe nerve pain, nausea, difficulties with speaking, sight, swallowing and eating, seizure like brain activity, intermittent paralysis, contractures in hands and feet etc were left un-investigated and untreated.”

This sufferer states how: “I could see the sense in graded exercise and how it could help someone to comeback from an illness and aid in their recovery but unfortunately with ME this treatment does not work and just sets you back”.

“It is totally unacceptable that I should be put through this distress because of ignorance about the severity and reality of my condition and disability, as a person really suffering with severe ME” asserts a sufferer.

“We wish of course that we could recover from the illness, and resume a normal life, with a little graded exercise/activity and a positive mindset. It would be the perfect solution without having to resort to drugs and the risk of side effects. But it simply doesn’t work for those correctly diagnosed with ME and in some cases can actually make matters even worse”, says this respondent.
“I no longer see medical professionals because it is so hard to tell who is biased and who is not until it is too late. The absolute worst are so called ME specialists as they do not admit that they think ME/CFS is a behavioural disease and they put on the charm offensive, they are such liars and cheats” another sufferer complains.

“ME patients not given proper consideration when the diverse range of symptoms are classed as being "all in the mind". As a consequence my own condition deteriorated to my requiring 24hr care with a rota of three nurses and my husband to care for me” this sufferer stated, showing how dangerous ill-informed treatment can be.

“CBT in particular is understandably appealing to the DoH as it’s an apparently cheap option to deal with an expensive problem. But it appears to be a red herring dressed up as a cure by those who seek to deny the physical reality of the illness” points out this sufferer.

And another sufferer tells how:

After exploration into Dr S’s methods (treatment with antidepressants) I declined to attend. Firstly my condition bears no relation to that of the one described as Chronic Fatigue & secondly, I’d been prescribed several antidepressants when I first became unwell. They produced near catastrophic consequences & I had no wish to repeat this experience!

**Conclusion**

This report paints a desperate picture. Surely our respondent was right to call this a “medical scandal” of gross proportions.

Despite the real danger of Graded Exercise Therapy being harmful to the severely affected, 44% of respondents were still offered this intervention.

Every survey of sufferers (and this one is no exception) seriously calls into question the efficacy of GET and CBT: 96% and 95% respectively of respondents who tried it said that it had a negative impact upon their symptoms, yet as this report shows, this is often the only “treatment” on offer to sufferers and is the one being vigorously pursued by Government.

Significantly more than half of those offered CBT or GET refused the treatment; that is because, as the study has shown, people are very aware and are simply not willing to be made worse. However the bleak reality is that more than half of sufferers, each one on average experiencing more than 20 severe neurological, autonomic and endocrine symptoms, are just being left to get on with it, with no treatment whatsoever, some for decades.

This report has presented shocking evidence of abuse at the hands of the psychiatric lobby. Our members have reported being locked in secure psychiatric wards or AIDS units and their lack of response to “treatment” being taken as an indication of their misguided thinking.

It is time to acknowledge and address the main issues underlying the reasons for this abuse.

Click here to read the entire document; many more quotes from severe M.E. sufferers are given in the text, as well as some high quality medical information, this text is highly recommended.

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**NOTE:** An * denotes that a name has been changed by request for the protection of privacy.
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 thin 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

It's 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 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 malaise 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.

Name: M.S. Country: UK (from the RiME website)

When I contracted ME, I was a young student. Doctors were unable to diagnose or treat the illness but they: maintained a professional interest, gave me (The patient) the benefit of the doubt, and were interested in learning more about ME.

The power and influence of the psychiatric lobby changed all this In recent times, I have either been treated as a psychiatric case who needs to be humoured or a difficult case that dues not fit into any medical category and which can be ignored.
I have been put on Graded exercise and CBT programs which have led to a deterioration in my health. Psychiatric bias and manipulation of the facts has adversely-affected the way that I and others are treated by GP's, Consultants, employers and family, even.

Betrayal of the Severely Ill? Appendix 12: Letter from QLD ME/CFS Society to the RACP Working Group

‘A young woman who had been hospitalised due to the severity of her illness (she was having difficulty remaining upright due to her blood pressure collapsing) was removed to a psychiatric ward against the wishes of her treating physician. The physician was actually threatened with the loss of his visiting rights to the hospital if he did not consent to the move. The young woman had a copy of the draft placed in her face with the "exercise bits" highlighted. She was told by an infectious diseases physician that she could expect to faint several times, but it was only through exercising that she would get better.

The staff have been saying to her that she is just a "naughty girl" (she's 26 and a qualified physiotherapist) and "doesn't want to get better". Her mother is currently sleeping on the floor of her room to prevent psychiatric patients invading it at night, or staff members verbally criticising her or attempting to make her do physical tasks beyond her capacity."

Name: Tim*

I was put on a GET programme, it was similar to the ones being prescribed today. Just like others whose pain, cognitive impairments, and bone crushing exhaustion, got worse I was told I had to push through it because and then things would improve.

Well I didn't improve instead I continued to get worse. GET not only set me back at the time, it left me more severely disabled and ill than I was before, I have never been able to get back to my prior level of physical activity.

My muscles and nervous system are badly effected, GET caused my exercise intolerance level too become even more disabling, so even on my good days the level of activity I can achieve is markedly less than before. The muscles I use most are now in a really bad way, I keep being told this does not happen in ME, but then many doctors now base their understanding of ME on the deliberately misleading descriptions of idiopathic chronic fatigue.

Name: Fox

GET is a horrible treatment for sufferers of REAL ME-CFIDS-CFS.

It might work for people with 'chronic fatigue' which is NOT the same as ME-CFIDS-CFS.

For me, it made nearly all my symptoms worse.

Name: Nicoletta Country: Switzerland

I am suffering from CFS for some years now, severely ill for more than a year, almost full time bedridden. After having tried a lot of alternative therapy I decided to give graded exercise a try-why not, it sounds so logical (to everyone who is not suffering from ME). I tried hard for about 10 weeks in hospital. Looking back I must that it did not help much, it put me under so much stress that I was not able to sleep without sleeping pills anymore. Even though the doctors were quite empathic, they did not notice that I was working above my levels. And after some time I was quite fed up to talk about my activities. I had the impression that doctors did not quite accept my limits and my experiences I had when going over this limits. It did not harm me much I think, but it was just another frustrating experience. In my opinion a bit of exercise, very well adjusted to the situation won't harm, for me it is walking to the mailbox once a day, sitting a bit in a chair outside. But graded exercise as practiced in hospitals is never ever a cure for CFS. My opinion is that those who get better would have gotten better anyway or did not have real CFS.

Money spent on Graded exercise is wasted money, in my opinion most people feel how much they tolerate and
make the most of it. A good physiotherapeut who shows some methods of stretching or possibilities of very light exercise might be useful

Name: Jaomi

GET: useless. i took part in graded exercise for several months as part of combined therapy with CBT. i found that no matter how small the starting amount of exercise, i got worse. it made joint and muscle pains worse. i was also mentally drained. i would say this treatment is useless and best avoided.

Name: Tim*

I believe any CFS patient forced into doing those treatments [exercise therapies] against their better judgement could be endangering their health mentally and physically.

Name: S.M. Country: UK (from the RiME website)

Over 13 years ago my brother contracted an unknown illness rendering him bed bound and hospitalised at the age of 18. In hospital he underwent tests and was put on a program of graded exercise which left him flat out, bedridden, hardly able to speak or feed himself and unbelievably in the geriatric ward, a totally unsatisfactory and inhumane treatment.

My parents took him out of hospital and have cared for him at home, trying to understand this illness. Until 18 months ago he had made progress and had reached a level where for short periods of time he could watch TV, use the Internet and get around the house in a motorised wheelchair. But after trying to get better to everyone's disbelief he deteriorated to a condition even worse than before.

He is now lying in bed in a darkened room, again unable to stand light and sound, unable to sit up in bed or even roll over. He can only move his forearms and speak for extremely short periods of time. He is being cared for, spoon fed and toileted by my parents and has absolutely no quality of life. This leaves my parents with a life of hard work and stress beyond belief and no rest.

I believe the only way forward with this illness is for the medical research council to fund proper research as stated on the petition. Everyone is entitled to some quality of life.

Name: Kate

I tried GET. However, I did it myself so people might not consider me a proper example, assuming I over did it when I had my relapse. However, I followed the accepted protocol very carefully. I increased my activity by only the tiniest amount and I then kept that level of activity up until I was sure it didn't have any detrimental effects before I attempted to increase again. It took me 6 months to walk to the end of my road (26 terraced houses) and a further six months to get to my local shop. I wore a pedometer to make sure I inadvertently didn't do more on good days. However, 1 and three quarter years after I'd started, I was at the shops and I suddenly realised I could walk no more. I used my mobile to get a neighbour to pick me up and that was almost exactly three years ago and I've been housebound since with no improvement at all.

I have a huge concern about how long any studies using GET follow up patients. If I'd been part of a study that had followed me up 18 months after I'd started GET I would've been a total success. However, two years later a different story. I feel very strongly that and GET study should follow up people 5 or even 10 years later.

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. It is only when the true physical cause for M.E. is found that the psychiatric dominance will disappear, just as happened with
Multiple Sclerosis and even Asthma, once the truth was revealed. 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: Adenton

It made the condition far worse.

Name: Patti

Despite about 8 attempts over 5 years, graded exercise hasn't ever worked for me. At one point, it did help me regain a little muscle strength and make me feel better about my body. I always stretched before exercising, began at 2 minutes on the treadmill, or 1 rep at whatever machine, rested between and worked up VERY slowly (adding a minute every 2 weeks). I was only ever able to get to 12 minutes walking on the treadmill without crashing. The first few tries, I kept at it, resting up after the crash and doggedly starting all over again.

But I found that I feel worse overall when I exercise than when I don't, so now I stick to stretching and an occasional tai chi workout on tape for elderly people. Side effects of graded exercise were excruciating. It was difficult at best, and the longer I kept at it, the worse I felt.

From the 25% Group, by an anonymous sufferer:

‘Governments, researchers and the medical profession in general need to realise that it is not just about saving lives but quality of life and that with severe ME, this quality is zero. Society would not let animals go through such suffering and incapacity but ME sufferers are left to exist in a "living death" state for years; sustained only by the distant ray of hope of recovery and a positive attitude that keeps you fighting and thinking that it’s got to get better soon even after years of disappointments.

Insult is added to injury by the fact that some people still believe a bit of graded exercise and some positive thinking is all that stops sufferers getting well. I used these methods to recover from an accident when I received 25% burns but with ME this form of "treatment" only results in deterioration rather than increasing your capacity! If only that was the answer I’d never have been in this hell. I’d have been well years ago enjoying the wonderful life I led before ME.’

Comments from Greg Crowhurst of the 25% M.E. Group to the Gibson Enquiry; December 2005

A sufferer recounts the often horrifying impact of this “treatment” [CBT and GET] regime on those with severe ME:

“All of my ‘help’ is useless:

I am offered anti-depressants (I am not depressed)

I am offered ‘Behavioural Therapy’ (I have no incorrect illness beliefs).

I am offered ‘Graded Exercise’ (Which even in small moderation, relapses me).

EVEN WHEN I DO THESE ALL AGAINST MY WILL. As an inpatient in Hospital, my medical records are falsified, and it claims I am ‘obstructive’ to my own recovery, as these psychosomatic principles have no effect on me. This is then claimed to be MY fault, not the fact that I am not mentally ill, and therefore do not ‘recover’ from M.E via mental illness interventions”.

The same sufferer goes on to tell how:

“I was refused medical drugs for chest pain and orthostatic intolerance (a feature of M.E) unless I agreed to be LOCKED in a mental institution in LONDON (National Hospital For Neurology & Neurosurgery) Summer 2004.
I participated in ALL activities I was asked to do, despite being mostly bed-bound.

I was not given food, and had to resort to hiding food in bags, and urinating in water bottles and hiding them under the bed (as I was refused to be pushed to the toilet).

Despite this treatment, I continued my ‘Behavioural Therapy’ at this Hospital and did everything they asked. On reading my medical records, it stated ‘had not engaged with the treatment protocol, and ‘self-discharged’. All lies and fabrication of the truth.

This is what ‘Behavioural Therapy’ is for an M.E patient in 2004 in the NHS”.

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**From the 25% Group, A carer’s story by Greg Crowhurst** (Commenting on the MRC report.)

I have got about an hour. It’s an early Thursday morning and a world away people are going to work, grabbing breakfast, starting a new day. My wife Linda is asleep. In about an hour I will do my best to help ease her agony. For if the last eleven years are anything to go by she will awaken in a darkened room paralysed and totally in pain. Her face will be drawn and palsyed down the left side. She will shake and gasp in awful thirst. Very gently, in whispers - for any noise is devastating, I will try to help her. I will probably get it wrong because even now, after eleven years of it, I don’t really understand the full extent of her suffering; how even the softest, most loving touch hurts.

Did I say eleven years? That’s a lot of mornings. That’s a lot of time with no treatment, no relief. That’s a big chunk out of a career. That’s a quite a bit of time surviving on benefits, living in isolation, fighting for just to be acknowledged for God’s sake. Somewhere out there a whole bunch of psychiatrists are probably climbing into their BMW Series 5’s as they too begin this new day. Me and Linda, we’ve spent the last eleven years surviving; because that’s the best you can do with Severe ME at the moment. Professor This and That meanwhile have spent the time building a nice little career thank you very much, cheekily suggesting that if only people like Linda could change their beliefs that they are ill, then.....I am searching for an analogy here, you know when you can’t get rid of a particularly annoying pest; something loathsome that crawls out of woodwork ... I don’t know, but I hope you get the picture, for that is how this carer - and I suspect I’m not the only one, views the Cognitive Behaviour boys. It wouldn’t be so bad if they’d just gracefully admit "it's a fair cop guv!" Okay you’ve done alright on the back of the likes of Linda with your mad ideas and theories, now just go away and leave us alone ! Will they heck!! Those blighters have only gone and grabbed for themselves £11 million quid. Eleven million pounds of our money!! £2.5 million for the Mighty Rich Con (Medical Research Council) scam and the rest for a hoary horde of psychiatrists to staff those ME treatment centres. If you and I had eleven million pounds, I wonder what we’d spend it on:

It wouldn’t be our first thought to spend it on someone to come out and put our loved one through their paces with 90 minutes of Graded Exercise "Therapy".· It just wouldn’t occur to us to send for a psychiatrist anymore than we’d expect a shrink to turn up and ask us if we’re sure, if we’ve broken down by the side of the road.

We would say "you’re having a laugh" if a man in white coat asked us to spend £2.5 million on a Missed Real Chance; that specifically excludes those suffering from ME !You and I , we wouldn’t waste time faffing around. We have the overwhelming evidence of our own eyes to go on.

We’d blinking do something so revolutionary it would be shocking. We’d spend a penny on physical research. And another and another.....we’d make some progress wouldn’t we ?

Controversially it might just be worth our while funding a CBT - Cut-out the Bollocks Therapy for those deluded behaviourists to attend, while the rest of the world wakes up. Ah well, More Rubbish and Confusion. Another day wasted.

**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.

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**Name:** Annette

I tried a weekly water exercise class starting at 15 minutes. The chemicals in the pool made me violently ill (nausea and vomiting) and the exercise made my ME symptoms worse. The muscle pain, weakness, sore throat/glands grew every week and although I stopped and started at an easier level it was impossible to continue.

I find the sea a better option but I am too weak to do this safely without help.

**Name:** SG  **Country:** Australia

When I was severely ill, and when I am in relapse mode, I can do little more than move from the bed to the couch. But on days when I can, I have to do some exercise, very carefully being aware of the signals that tell me to stop.

Interestingly, I've found that the type of exercise I can do is extremely limited. I can walk slowly for a varying length of time with rest breaks, and I can swim slowly. I've also tried yoga and pilates, but both send me into relapse.

**Name:** Nanaloo

I have walked for years and continue to try to walk now but the side effects are not worth it at this point. Hopefully, someday, I can enjoy it again.

**Name:** [Name supplied]  **[Online]**

I am writing to tell you what I know about Dr Trudie Chalder. She was consulted about the treatment of my son whilst he was in hospital. My son, who is 20 now, was admitted to a hospital in the District for rehabilitation with his ME. He was severely affected and bedbound and unable to care for himself. Since his discharge I have obtained the medical records and I can see that the consultant in charge wrote to Dr Simon Wessely for advice. I
presume he referred the request to his colleague Dr Chalder. On my son's hospital file is a document, dated 07-03-01, a 'Draft Action Plan Proposal following consultation with Trudie Chalder' which I attach. I find the action plan shocking, and I was particularly disturbed by the penultimate paragraph which states:

"We expect (name) to protest as well as the activity causing him a lot of pain. This may result in screams. . . . it may feel punitive."

What I witnessed in the hospital was certainly punitive and I often saw him handled roughly and his skin marked.

This plan has never been discussed with me. I was unaware of it's existence, in fact when I spoke to the consultant asking where he was getting his advice about treatment for ME he refused to tell me. I never gave my consent to this action plan.

There was a parental meeting about physiotherapy being painful, and I was specifically asked whether I consented to this. At the time I understood the question to concern normal physiotherapy, and did not realise that I was being asked to consent to a painful psychological action plan, in the file is a note by the physiotherapist stating that pushing into my son's contracted hamstring would cause pain. He was told "that is the point".

I believe this explains why my son was never offered pain relief; and although I asked for it several times I received no response, There were a number of painful incidents; he was found bleeding from the stomach in February 2001 and duodenal ulcers were detected in September 2001. He also had surgery in September 2001.

On 18 April 2001 I wrote to the consultant about the pain my son must experience in having a nasogastric tube frequently inserted. I reported that it had been reinserted 11 times in the previous 7 weeks and asked if steps could he taken to avoid the frequency of such an invasive procedure. I have no record of receiving a reply.

The Action Plan also accounts for the diagnosis of "elective mutism" which was then applied to my son. This in itself has caused him great harm both before and after his discharge as everyone treats him as though he is refusing to speak. Community speech therapists have refused to work with him on the basis that he might "not be compliant or not in the mood". After three referrals one did visit him once but she appeared to have been warned by her medical director not to put anything in writing, for fear of challenging that diagnosis.

During his time in hospital all the other young people on the ward were continually told that my son could speak, and could move, but was choosing not to. They would frequently ask me why he chose not to speak. The nurses would say, "It's a lovely day, what a pity you're not out there", as though he could be if he wished. Day after day he was treated this way.

He was admitted to the hospital on 14 December 2000, initially for a three-month assessment. At the family meeting on 25 January 2001 it was stated that the final review would be on March 15 2001 and if there was no progress towards free communication a discharge plan would be agreed with the family. My son's lack of speech was clearly seen as the most serious of his disabilities.

In the file is the occupational therapy review dated 15 March 2001 recommending, "Team to debate the approach following recent consultation with ME specialist", which I presume refers to Dr Chalder. The occupational therapist then appeared to take on the role as lead therapist. There is a record of a confidential meeting on 31 May 2001, which agreed to continue with the behaviour programme. It states that, "The Chronic Fatigue Service believe that this (exercise programme) is not to prevent contractures as (name) is moving and being moved enough to otherwise prevent this, but to pursue exercise to the point where he resists." The service referred to above is the one at Kings College Hospital.

At a team meeting on 28 June 2001 a provisional discharge date was set for August. In the event he was not discharged until 10 January 2002.

Until discharge the behaviour programme continued to be increased and I attempted to resist this. I wrote to the consultant and eventually complained that it was too much for my son. The response was to increase the programme further. The consultant stopped speaking to me on the unit. I then discovered that he had behaved unprofessionally because in a referral letter he stated my son was suffering from "pervasive refusal syndrome", which had never been said to me. I then realised I had been completely left out of the loop identifying my son's illness and his treatment, I complained to the Chief Executive of the hospital Trust. An investigation was promised but this never happened.
The hospital did not want to discharge my son home. They tried to refer him to two brain damage units who would not accept him, as they were not appropriate referrals. Finally a letter was written to the consultant from the House of Lords, urging him to allow my son home. Coincidentally he was discharged home soon after.

The issue of my son's consent is frequently referred to in the notes, and it is clear throughout that they did not have his consent.

This unfortunate history is a case study of what can happen when diagnosis and treatment are not discussed with the patient and his family. There was no consent to the "treatment" which caused pain and suffering. I believe that the action plan had the effect of making staff who carried it out indifferent to my son's pain and safety. He was treated with less and less respect the longer he was on the unit, not least because he failed to respond. The longer this went on the harder they tried to make him respond. By the end he was not being treated with any respect. I believe therefore that the action plan devised by Trudie Chalder was harmful and posed unacceptable risks.

There was no appraisal of evidence as to whether or not the programme was working. It is not in dispute that my son made no improvement at all during the 12 months spent in that hospital I believe Dr Chalder has stated that "parents... hold physical illness attributions resulting in them searching for a specific physical cause"
The implication is that to do so is both unhelpful and wrong. She must be asked to what she attributes the illness.

The approach of Dr Chalder and the Chronic Fatigue Service is diverging from Department of Health policies, like the expert patient programme, and the Report of the CFS/ME Working Group to the chief medical officer, which recommended that management should be undertaken in partnership with the patient, and should be applied flexibly in the light of their clinical course. Please note that she resigned early from the working group, as she did not agree with the findings.

An action plan, such as the one attached, is not respectful of the patient, could not be discussed with the patient, or carried out in partnership. It is not good practice to cause patients "a lot of pain", I question whether it is ethical, indeed it may be unlawful.

May I draw your attention to the controversy raging at which Dr Chalder is at the heart. She and colleagues published an article in the BMJ in September 2003, "Epidemiology of chronic fatigue syndrome and self reported myalgic encephalomyelitis in 5-15 year olds". This has been followed by a stream of incandescent correspondence. (bmj.bmjournals.com/cgi/eleter/327/7416/654#36770).

Articles in the press, such as the recent one in the Times "Chronic Fatigue Syndrome : Tired or emotional?" September 27 2003, echo the row going on in the field, Dr Chalder's position is extreme and I hope the Department of Health will consider carefully whether it wishes the Chronic Fatigue Service, of which Dr Chalder is a member, to have any role in proposals for new services for patients with ME.

Name: On behalf of EAN PROCTER [Online] Country: UK

1Without ever having spoken to his parents, social workers supported by psychiatrists and armed with a Court Order specially signed by a magistrate on a Sunday, removed the child under police presence from his distraught and disbelieving parents and placed him into "care" because psychiatrists believed his illness was psychological and was being maintained by an "over-protective mother". Everything possible was done to censor communication between the child and his parents, who did not even know if their son knew why they were not allowed to visit him.

In this "care", the sick child was forcibly thrown into a hospital swimming pool with no floating aids because psychiatrists wanted to prove that he could use his limbs and that he would be forced to do so to save himself from drowning. He could not save himself and sank to the bottom of the pool. The terrified child was also dragged out of the hospital ward and taken on a ghost train because psychiatrists were determined to prove that he could speak and they believed he would cry out in fear and panic and this would prove them right. Another part of this "care" included keeping the boy alone in a side-ward and leaving him intentionally unattended for over seven hours at a time with no means of communication because the call bell had been deliberately disconnected.

The side-ward was next to the lavatories and the staff believed he would take himself to the lavatory when he was desperate enough. He was unable to do so and wet himself but was left for many hours at a time sitting in urine-soaked clothes in a wet chair. Another part of the "care" involved the child being raced in his wheelchair up and down corridors by a male nurse who would stop abruptly without warning, supposedly to make the boy hold on to...
the chair sides to prevent himself from being tipped out; he was unable to do so and was projected out of the wheelchair onto the floor, which on one occasion resulted in injury to his back. This was regarded as a huge joke by the staff.

In a further medical report dated 5th August 1988 for Messrs Simcocks, Wessely expressed a diametric opinion from that of Dr Morgan-Hughes, writing: "A label does not matter so long as the correct treatment is instituted. It may assist the Court to point out that I am the co-author of several scientific papers concerning the topic of "ME"...I have considerable experience of both (it) and child and adult psychiatry (and) submit that mutism cannot occur (in ME). I disagree that active rehabilitation should wait until recovery has taken place, and submit that recovery will not occur until such rehabilitation has commenced...it may help the Court to emphasise that...active management, which takes both a physical and psychological approach, is the most successful treatment available. It is now in everyone’s interests that rehabilitation proceeds as quickly as possible. I am sure that everyone, including Ean, is now anxious for a way out of this dilemma with dignity”.

Ean Proctor was kept in "care" and away from his parents for over five months. Although this took place in 1988, such brutality is still happening in the UK: the continued barbaric "treatment" of sick children by certain psychiatrists who profess to specialise in ME was the subject of a Panorama programme transmitted on 8th November 1999 and was profoundly disturbing (a videotape recording is available).

Nothing seems to have been learnt from the appalling case of Ean Proctor and there is no question that children with ME continue to be forcibly removed from their parents and home; this issue was raised by Dr Nigel Speight, a consultant paediatrician at the University Hospital of North Durham with 20 years experience of children with ME, who in April 1999 reported to the Chief Medical Officer’s Working Group on "CFS/ME" that the frequency of psychiatrists diagnosing the parents of children with ME as having Munchausen's Syndrome by Proxy now amounted to an epidemic. Jane Colby, Executive Director of The Young ME Sufferers Trust (TYMES Trust) says "To have your sick child taken from you, to be suspected of damaging them yourself, just when they most need your care, is an appalling experience".

See also:
**The Ean Proctor Story**
**Ean’s Story** by Barbara Proctor, Ean's mother

Ean’s case is also mentioned in:

**To set the record straight about Ean Proctor from the Isle of Man** By Eileen Marshall and Margaret Williams, 20th July, 2005

**Inadequacy of the York (2005) Systematic Review of the CFS/ME Medical Evidence Base.**
Comment by Professor Malcolm Hooper & Horace Reid, January 2006

**Another Meadow?** by Eileen Marshall and Margaret Williams, 16th July 2005

**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)**
bymargaret Williams et al. 16th January 2003

**Name:** A.H.  **Country:** UK (from the RiME website)

Before March 1994 I was fit and healthy and employed as a Head of Year and PE / Maths teacher who led a full and active sports life. On 8th March 1994 I suffered a strange debilitating virus which eventually became so bad I was unable to work, (incidentally, there was a cluster of cases of M.E, affecting to varying degrees, a number of pupils at the school.) I paid for tests to be undertaken privately and these proved that I was suffering from Post Viral Syndrome, following Glandular fever. The NHS solution was that nothing could be done but it probably go within two years, which I refused to accept and set out to find the solutions privately.

During the following three years I deteriorated until in 1997 I was reduced to crawling to the toilet, being carried downstairs and spending the day lying as still as possible due to severe agonizing headaches. In addition I suffered from terrible weakness, muscle aches, severe dizziness, blurred vision, sore throats, sweating and shivering, swollen glands, highly light and noise sensitive and digestive problems. I was barely able to sit up to eat, unable to watch TV or even converse for more than about 5 minutes,...

Every day, seems like eternity, spent enduring pain, feeling so ill, like your blood has been poisoned, with the frustration of being trapped inside a useless body, unable to concentrate and needing assistance to do the most
basic tasks. For a couple of months I suffered the humiliation of being unable to feed myself. Whilst I am able to do this now I still need help to get to the toilet, to wash and dress etc.

it is like the seasickness adage. First you feel so ill that you are afraid your going to die and then it gets worse and you are afraid you are not going to die. I and most other sufferers, adopt a determined, positive and proactive attitude, which no doubt contributed to ME in the first place. Merely surviving these eight years of hell has been a far greater achievement than any of my academic qualifications, sporting achievements or job promotions.

Over eight years I have spent thousands of pounds, in vain, seeking a solution from many sources including ME Consultants, Acupuncture, Osteopathy, Homeopathy, Herbal medicine, Nutritional therapy, Kinesiology, Hypnotherapy, various healers, very many nutritional supplements. Immunogiobin, B12 and magnesium injections with little or no help from the NHS.

Governments, researchers and fundraisers need to realize that it's not just about saving lives but quality of life and that with severe ME this is zero. Society would not let animals go through such suffering and incapacity but ME sufferers are left to exist in a "living death" state for years sustained only by the distant ray of hope of recovery and a positive attitude that keeps you fighting and thinking that it's got to get better soon even after 8 years of disappointments.

Insult is added to injury by the fact that some people still believe a bit of graded exercise and some positive thinking is all that stops sufferers getting well. I used these methods to recover from an accident when I received 25% burns but with ME this results in deterioration rather than increasing my capacity. If only that was the answer I'd never be in this hell I'd have been well years ago enjoying a wonderful life that I had before ME.

It is a disgrace that there is no government funding research into aetiology of ME, (the only funding is provided through charities and donations, for an illness which affects an increasing number of people of all ages, usually the very active) I urge you to ensure that this criminal neglect is ended now with desperately needed funded research into Neurology, Immunology, and other areas of dysfunction. Severely affected sufferers must be included in any study, not just those well enough to attend the trials.

Name: N.B. Country: UK (from the RiME website)

When first ill, after two and a half years in bed, I spent six and a half months in a psychiatric ward - the only help they offered on the NHS, I did graduated exercise and CBT. It did not cure me, I am still badly disabled with ME after 12 years and use a wheelchair.

Name: J.W. Country: UK (from the RiME website)

I am writing in great despair. I have been a M.E sufferer (Myalgic Encephalomyelitis) now for 14 years. I have had this since the age of 16, I am now 30 and have had my life ruined and taken away by this very misunderstood illness. I live day to day trying to cope with an array of symptoms and as there are no doctors who really know how to help or even all the symptoms you can suffer from.

I know there are many people worse off than myself, but that does not give the Government the right to make no effort in funding any sort of medical research, to find a cure for M.E sufferers and for us to be treated like second class malingerers by the doctors. We all need help to find a cure for this covered up illness now. Why should we have to suffer in silence alone?

Many M.E. sufferers have taken their own lives through sheer despair and I have the lost a wonderful friend to this and do not want to lose any more before you realise how awful this illness is. I suffer from breathing difficulties, heart irregularities, confusion, pain, muscle weakness, head pain, swollen lymph nodes, fevers, sickness, dizziness, severe unreality, shaking, have to use a wheelchair when I'm out and am pretty much housebound. This is some of the symptoms I suffer. I want medical funding for research. It is my right and I want it before the next 15 years of my life are ruined.

Name: R.I. Country: UK (from the RiME website)

The exclusion clause, "... but with the exception of psychiatry," in your petition, appealing for a co-ordinated research programme into the aetiology (underlying causes) of ME, begs the question why psychiatrists should be
involved in the treatment of people with M.E., unless they have a history of, or a concomitant, psychiatric illness. It is understandable that people with M.E. are fed up with the loss of career (or interruption of education in children), reduced standard of living, social isolation and fractured relationships, sometimes compounded by disbelief & derision, on top of the discomfort of the illness, but this is not the same experience as clinical depression, which is not thus explicable.

Of course, some people with M.E. may have depression, or some other psychiatric illness, but the one is not a prerequisite for the other.

Since M.E is classified as a neurological, not a psychiatric or mental illness, it may, at first, appear hard to see why psychiatry has taken such a dominant role in research and treatment.

A significant reason for this may be the influence of the report from the Royal colleges of Physicians, Psychiatrists and General Practitioners in 1996, since when Chrome Fatigue Syndrome has been widely thought of as the official name. Why CFS should be the preferred term has never been made clear by those who said it should be so.

Chronic Fatigue Syndrome is an umbrella term, under which a number of illnesses, in which chronic fatigue is but one symptom, are contained, ME. is much more than mere tiredness The terms are not interchangeable as putting a / between them suggests.

Since we are not talking about the Same illness, there ought to be different research strategies and the treatments suggested by findings as suitable for one condition, for example graded exercise or cognitive behavioural therapy, may not be suitable may even be harmful - for the other.

Thanks for your initiative [RiME], from all with ME but in particular on behalf of those who are so severely affected that they remain isolated, invisible, without a voice and, in spite of receiving particular mention in the CMO's Report, are still neglected

Name: P.L. Country: UK (from the RiME website)

As a social worker, I have met several people with this illness, I was very surprised to hear that the Government is funding no research into its underlying physical causes.

In addition to the human suffering there is the question of cost. ME currently costs the country over £4 Billion pounds per year The state has a duty to investigate. What is behind this much misunderstood illness and enable people to improve / recover so they can resume a useful role in society.

The small sums of money which up to now have been spent on psychiatric models of treatment are not working and are inappropriate.

Name: Clair Coul

I was diagnosed with ME when I was 15 years old. I am now 30 years old. When I was 21 years old I saw a doctor at my local hospital's Pain Clinic. He did a brief examination and declared that I didn't have ME anymore and that I was unfit. The only way I was going to recover was if I did a course of physiotherapy. I knew he would label me a fraud if I didn't attempt it so against my better judgement I agreed.

At this time I was using a wheelchair outdoors and a walking stick indoors. My symptoms were quite severe and fluctuated a lot. The course of physio involved going the to the local hospital (using volunteer transport) twice a week to do a set of exercises. The transport arrangements were not well organised and I was often waiting up to an hour to be picked up or taken home. I was given two pages of exercises to do. They were apparently the simplest and easiest they did. At my request I was supervised by an assistant physio, I would have been expected to complete all of the exercises on my own.

The exercises comprised of:
- Sitting with 1KG weights on my ankles, raising and extending my legs for 10 repetitions.
- Raising my arms above my head for 10 repetitions.
- Raising and lowering my shoulders for 10 repetitions.
- Holding a stick with both hands, extending arms and raising it over and behind my head.
Sitting on a wobble board and rotating my hips for 2 minutes
Standing at the wall bars and raising each leg behind me and to the side, for 10 repetitions of each.
Plus quite a few more exercises I can't remember the details of at the moment.

I was expected to complete all of the these exercises in the first sessions and increase the number of repetitions each session after that. In the first session I was unable to complete all of the exercises, I had to do the standing exercises laying down as I could not stand for that long. when I was taken home I collapsed through the door. I managed to crawl across the floor to the telephone to call my mother for help. This happened after each session.

The volunteer driver who took me to the hospital asked me one day what they were doing to me because they were making me worse not better. Over the 5 weeks that I did the physio my ME became much worse. I had no quality of life, I was just eating, sleeping and doing physio. I [was too ill] to do anything else. My pain had significantly increased and my mobility decreased. After 5 weeks my husband wrote a letter to the hospital telling them how ill I had become and that I would not be going to do physio anymore.

I saw the doctor at the pain clinic a couple of months after that for a follow up appointment. He mentioned the physio and his only comment was "I'm surprised you lasted that long".

Since then I have learned to pace myself and limit my activity and even though I am still quite severely affected by ME I have been stable for several years.

Name: Ken Country: Australia

I'm trained as an Occupational Therapist, so I was skilled in using graded exercise (or activity) therapy. However, even with my skilled background, it took me seven years of trial and error to get my activity balance close to right. Even now, it is a tightrope as precarious as any I have walked, and there is no safety net.

For me the critical issue is recovery time, both on the micro and macro levels. I dare not do the same activity (i.e. walking) every day. I am less prone to crashes and flare ups if I use a variety of different exercises (walking, swimming, weights and bouncing on a swiss ball). I do better if I break my exercise and activity into small chunks (10 minutes) with rest in between. I am severely affected by the total amount of activity I do in a set period. I can do a full days work once a week with almost no ill effects. Two days pushes me to the edge. If I am foolish enough to do three, my wife begs me to stop, and a relapse lasting 2-3 weeks is assured.

I cope with "sedentary" activity much better if I take 3-5 15 minute absolute rest breaks spread throughout the day. From watching and working with others with CFS, I know I am actually a "lucky one".

There is good CBT and bad CBT. The critical difference between the two is the issue is control. In spite of what many esteemed professionals think, most PWC's know their condition better than anyone else. Most tend to overestimate their capacity. CBT or GET that pushes a PWC is likely to fail, through relapse, withdrawal or refusal. Sensitive, responsive therapy may help, but lets be realistic here. Any gains made are likely to be modest at best - if you doubt it, look at the research.

Scientists get excited about "statistical significance", but the actual size of this difference is always small, if it is found at all.

Name: Sue Country: UK

I'm Sue, mum to Lauren 19, who has been ill for 8 years. Lauren isn't well enough to write herself so I hope you don't mind a second-hand account.

Lauren was disbelieved by the first paediatrician she was referred to at age 12. This woman told her to do as much as she could, to get up at her normal waking time for school and then to go to school as normal. The second consultation a year later saw us berated as a family for "giving in" to Lauren and the implication was that she was school phobic or being bullied.

We were told to increase the activities she was doing and she would soon get better. I guess this isn't classic GET but the effects were the same – a total and utter "crash" which means that Lauren is now mostly bed bound, housebound and has to be helped to bathe (and sometimes to eat). I enclose an extract from a letter of complaint we sent for illustration:

www.hfme.org
"During that meeting our whole family was distressed by the inferences that Dr. xxxxx chose to draw in order that she might explain Lauren's illness. We were told that Lauren, being an only child and attending a fee-paying school, meant that she "was under a lot of pressure to succeed" and that anxiety could be manifesting itself as these physical symptoms. She went on to say that if Lauren failed to "progress" with encouragement to do things and get on with life, then a spell on a ward for some psychological therapy would be suggested. We felt this was extremely intimidating and unhelpful.

Lauren was diagnosed two weeks later as having M.E., after our GP agreed to refer her to a paediatric specialist in Myalgic Encephalomyelitis. He recognised the very real and very physical symptoms for what they were and are. Over the seven years in which she has been ill, her health has deteriorated to the point where she has to use a wheelchair if she leaves the house. She receives Disability benefits and is very limited by her illness."

I know of other cases similar to Lauren but don't know whether their parents are up to writing.

Name: Rhonda Country: Australia

When i first got sick with me/cfs in 1992, after a flu type virus, (and I was painting) i did try to do walking, as i had been doing it before i got sick. each time i would do it, i would get sicker. and i did not make improvement until i stopped. and actually did less. i was able to go into 100% remission from this illness, after two years, taking nothing but antihistamines. and i don't think they helped. i think the rest did.
i got a tummy bug in 1998, after christmas, me.cfs came and grabbed me again on the 28th December. i tried to push on this time as i had got well before. i kept getting sicker and sicker. i tried walking, to the corner. And further. but i had to get my husband to come and get me.

I have improved quite a lot since a few years ago, but that was done through medication, pacing, and management. I am active now & I cannot see that it is has helped me in anyway at all. i still have a sore throat, am limited in what i do, suffer huge set backs, in actual fact, i find that the more i do, on any day, i actually feel worse i am still in the process of cutting back on what i do.

most people want to do more, not less.

A person not knowing anything about ME/CFS should never be allowed to put [treatments] into place. if someone does not realise that sitting in a chair, is the first step, and does not realise how hard this is, and may even make things worse, then they do not know what cfs is. it must be considered and accepted that this illness is unique, in that post exertional malaise is a symptom. and that some people are severely bed ridden.

Name: [Name supplied] Country: US

Exercise intolerance means just that.

Name: Jodi Country: Australia

If exercise helps, you never had M.E. I had a moderate case of ME initially....if only I had known to rest instead of to being advised to exercise as much as possible that might still be the case. Or I might even have improved somewhat, or even be leading a somewhat normal healthy life.

As it is I now have extremely severe ME. I haven't been able to leave my house in a year (except for a trip to the emergency room for what turned out to be potentially life-threatening cardiac problems) and I have been almost completely bedbound now for the last 5 years and need carers to help me with the tasks of basic living - I'm only 29 and life for me now is just a living hell.

Whatever you do if you have ME DO NOT exercise past your limits, particularly in the early stages. There is evidence that if you do you can cause yourself serious and permanent damage (damage to the heart for example).

If exercise helps then you never had ME in the first place as a complete intolerance to even mild exercise IS WHAT ME IS. So any claims that exercise can improve the condition of a person with ME are fatally flawed. All of them. Studies showing improvements patients who increased their exercise levels DO NOT CONTAIN ANYONE WHO ACTUALLY HAS THE ILLNESS MYALGIC ENCEPHALOMYELITIS. Many researchers, looking at how patient populations are chosen for these studies agree such studies are on those with chronic
fatigue and not ME - in other words they have a completely different illness. No study has ever shown CBT or GET to be in any way helpful – or even safe – for patients with ME – NOT ONE. A large body of evidence also exists which shows how harmful or useless these approaches are for ME.

Please, if you have ME, rest - it’s your best chance to get at least some of your life back. It is bad enough any lives have been devastated as mine has been (or worse) by ignorant advice to exercise, but it kills me this is still happening despite so much evidence contradicts these very poorly designed and flawed studies on tired people who do not have ME. Nobody seem to care how utterly unscientific this ‘science’ is and people with ME are paying the price for that; a horrific price all just to save the Government and others a few dollars. It makes me sick.

Name: [Name supplied] [Online]

"I was in the prime of my young life when I became ill. I had a successful career, relationship, active social and sporting life. It was all lost at a promising point in my life. Now over 14 years later I am still too ill to regain any of it.

I was referred to take part in the CFS clinical trial (they didn’t believe in the term ME, or that a distinct illness of ME existed) at Withington hospital in the early 1990’s after I had experienced almost two years of continuing ill health following a sudden viral illness.

I first saw Dr. Richard Morriss (who was a senior registrar in psychiatry at that time - now a Professor at Liverpool University I think) who took my history and a number of blood tests.

He was very interested in the ‘mental’ symptoms and dismissed others that I felt were important which he obviously did not. I was subsequently enrolled in their study of antidepressants and Graded Exercise Therapy (GET).

Dr. Pearson passed through the room during this initial consultation and was very derisory about Clare Francis, the ME charities and the term ME itself. (Clare Francis is the Round The World Woman Yachtsman, an ME sufferer herself.) This was the only time I saw or had any contact with Dr. Pearson. I was led to believe that fluoxetine was a drug that would only be available to me if I took part in the study. I was never told at that time that I could have it (Prozac!) from my G.P. on ordinary prescription if I so wished at any time.

Because of this, I agreed to take part in the trial. I attended the clinic for 5 months at weekly and then monthly intervals. During this time I only ever saw Ricky Mullis (physiotherapist) and Alison Wearden (psychology post-graduate student).

I was given what I eventually discovered was a placebo and I was ‘encouraged’ to do more than I felt well enough to do. At each assessment I was required to go on an exercise bike for as long as I could. This did nothing for my state of health! Over three months I deteriorated considerably, became very frightened and eventually depressed (I wasn’t when I entered the study!).

I expressed this to Alison Wearden each time I saw her yet I was never referred to see any of the doctors despite my repeated requests for this to happen.

Eventually a relative of mine demanded we see a doctor and I said I no longer wished to participate in the study, as I was getting worse not better. Ricky Mullis (physiotherapist) vigorously tried to persuade me to stay on the trial regardless of my deteriorating physical and mental condition. I refused to do this and again demanded to see a doctor. I eventually saw a senior registrar in medicine. Only the second medical consultation I had received since initially attending.

I felt so ill and was so frightened and depressed that I was admitted to the hospital. The ward staff told me that only I could make myself better and ‘to get a grip’. On the ward I saw a senior registrar in psychiatry who prescribed a tricyclic anti-depressant, which he assured me gave me great hope of a recovery.

Whilst staying on this ward, I met two other people who had been diagnosed as having ME prior to attending the hospital, and they were told that if they did not take part in the trial, they would receive no other treatment, and so felt they had to take part to be able to do anything to feel better.
It was at this point I began to question the ethics and motivation of the study. After a few days in the ward, I had seen and heard enough and decided to go home!

A close friend at that time said all along the doctors and students running the trial were more interested in their research than they were in the welfare of the patients. I had not been depressed before I was ill or during the time I was ill until I attended the Manchester hospital. My own doctors would confirm this. I took the anti-depressants still believing that they would make me better. I returned to the outpatient clinic 6 weeks later, waited three and a half hours to see a house officer, who told me all my tests were normal and that there was nothing wrong with me.

As you can imagine, I was rather taken aback by this. I asked to see Dr. Pearson or one of the senior doctors. The house officer went off presumably to confer with someone else (Dr. Pearson I presumed), and returned to say that I could not see anyone else as I had chosen to withdraw from the study, so no further treatment was available to me.

I was given no further appointments, despite my insistence of how ill I still felt. The antidepressants did eventually lift the depression, but all my ME symptoms still remained. (I have not had any need for anti-depressants since this time and actually feel much better without them!)

In fact, my mobility was much reduced after attending this trial. Previously my mobility had been better than it was subsequent to my treatment in this Manchester Hospital and this condition continued for many years. (I now practice “pacing” proper and manage much better!)

So their ‘treatment’ left me worse and more debilitated than I was before I entered the study! I felt there was no concern for me as a human being and there was no further contact with me to see how I was doing, except a request some years later for me to take part in further research, which as you can imagine I quickly declined!

After this I began to hear from others their experiences of this same research team and became increasingly alarmed about what was occurring. I began to see many flaws in their trial. People enrolled in the trial were allowed to continue to take other treatments and to have other therapies, such as acupuncture and homeopathy independently, during the trial period. The doctors knew about the patients having other treatments independently during the trial period and yet these patients still remained in and were part of the trial and its results.

This negates the whole purpose and the validity of a randomised, double-blind, placebo controlled trial and therefore the results. I am therefore astonished when I see that the results have been published in a reputable journal * and are frequently quoted in other work.

I also became aware that there were a broad range of patients and conditions being enrolled in the study. It was clear that people with ME were being enrolled, but also others with other “fatigue” states of a variety of aetiologies. The CFS trial appeared to be an ‘umbrella’ including anyone who reported "unexplained fatigue" or "an absence of any signs of physical illness” (their words not mine).

I became aware of people with ME who were being prescribed 20 minutes exercise three times a week and who were also getting worse not better. My own doctor was amazed at what I reported to him about what was happening at this Centre. He stated that if he had known, he would never have referred others there. My own doctor was outraged at what had occurred. He has remained adamant that I had a genuine physical illness and that I was never ill through psychological problems or depression.

I never complained at the time, as I was so ill. It is only with hindsight that I can see what was happening was not helpful or useful and indeed damaging to some people including myself.

This was a teaching hospital and a so-called Centre of Excellence. It is therefore a scandal that this trial was conducted as it was and that the results were published and taken seriously by others in the medical profession when there was so many flaws within it and extremely poor and disrespectful treatment of patients. It was poor scientific research with no concern for the patients involved.

As patients, many people place their trust in doctors to help them recover. They do not expect disrespect or for the treatments to make them worse. A sick patient probably never contemplates that a doctor or their prescribed treatments will do them more harm than good!

As a result of this trial, I would be reluctant to take part in any other clinical trials and would advice others to proceed with caution. This trial has done a disservice to medicine as a whole and to patients.
I am therefore annoyed every time I see this trial quoted as published research as I know that what went on was not good quality research. It had many flaws.

With regard to their published findings, so much for their commentary (regarding high drop-out rates) that "Of the 21 drop-outs assessed at 26 weeks, there was no worsening of fatigue, functional work capacity, MOS health perception or depression" and "graded activity may provide patients with reassurance that exercise at a controlled rate need not exacerbate fatigue"!

I know of at least three others who were in the exercise group that were made so much worse!"

* Reference:

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Name: Karen Country: Australia

I have had CFS since late 97 which became worse after a bad flu and pneumonia in early 99. I was also nursing my mother who was dying of multi system atrophy. I was diagnosed with FMS later that year and was told to see a physiotherapist, she started me on 10 sets of 10 basic stretch exercises.

After 1 week I was in so much pain that I would grit my teeth and cry after exercise every morning and have to go back to bed for most of the day. After 2 weeks I cut the exercises to 5 reps and found that I couldn't do anything else during the day. I was showering twice a week with help and had trouble even getting to the toilet.

I stopped exercising totally for a week just so I could get to my appointment, when I got there she told me no pain no gain and she wanted me to continue and then to start gym work in a fortnight or I'd never get better. I never went back.

It took me months to recover enough to do a few things for myself and my pain has spread to most of my body now instead of just my back, shoulders and head.

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Name: Brooke Country: Australia

If it weren't so expensive, it would be laughable when doctors tell you that there's really nothing that they can do for you (except to recommend plenty of rest and pacing of activity) and then in their next breath turn around and schedule another appointment for you to come back and see them! As if you're going to pay another $100+ to be told the obvious?

It is ironic that doctors think that someone with M.E. needs to be TOLD to rest and not engage in too much activity; that we need this golden piece of professional advice (as if it hadn't already occurred to us ourselves)! For someone with severe M.E. isn't it kind of obvious that even if they wanted to, they COULDN'T do anything but rest! And the notion of 'pacing' your 'activity' levels! It's absurd. When I was at my most ill with M.E. my activity level was limited to things like sitting up and brushing my teeth- even then I couldn't do that without rest breaks! Pace my activity levels? "Gee doc, thanks for that great advice, I would never have known..."

What do doctors really think 'pacing' 'activity' levels is for a person with M.E (in as much as, that they feel that they need to TELL us to do these things)? Do doctors think that we have to be TOLD not to engage in 'too much' activity?! It's not like you can pace activity when your body won't let you engage in activity in the first place! It's not like we're small children who need to be told to "slow down, don't eat too much or you'll make yourself sick". Our bodies have already put in place a mechanism that makes it physically impossible for the severely ill to do too much in the first place! We can't pace that marathon in order that we get to the finish line, because we can't even stumble up to the starting line!

When I was at my worst with M.E, all that my body would allow me to do was rest.
Name: Erik* Country: Switzerland

I am writing in behalf of my son (16 since 2 weeks), ill since december 2003 (eg. almost 18 months now), just got a week ago a diagnosis from a brave pediatrician, not yet acquainted very much with cfs/me and ready to read through all this documentations (canadian guidelines, etc. etc.). My son still being in danger of being harassed by schooldirector and child protection authorities and psychiatric clinic.

Was recommended a GET and behavioural therapy by the chief of a departement of children hospital. My son is homebound ever since he got november last a yeast treatment from a doctor (Perenterol), as of his most serious additional belly problems.

He does not think at all that this form of therapy will help him at all, as he sees already without this how little it takes to overexert himself (eg. the visit at home of a kind doctor), he does suffer serious post exertional malaise and eating is getting always a problem.

I am writing you from Switzerland, where just a short time ago a professor published in the swiss medical weekly an article saying that cfs/me is a psychiatric disorder and closely relied to fear traumata, fear denial, depression and other crap.

I do know after seeing the condition and the changes therein for such a long time now and after running from doctor to doctor first, that the medical personal are to a big extent a very strange kind. (I am really so sorry to say!)

My son would state here that you also could treat a broken leg with psychiatry if you would not know better.

And that never a doctor would get the idea to send somebody with a broken leg on a marathon; something which seems to him would be a good comparision of what was asked of him sometimes!

He just was not taken serious till we were lucky to find this pediatrician now.

And what my son does not know, the authorities are still seeming to go on... I really hope they will understand!!!

Name: [Name supplied]

Aggressive exercise at pain center in Cleveland. Forced myself to follow their program. Exhausted, all pain & symptoms exacerbated. Never got back to my formerly low level.

Name: Sharon*

GET: disaster for me. Despite tests indicating muscle metabolism abnormalities I was treated with this whilst an inpatient. Like others I was told I had to work through the pain and increased malaise. As a result I became more severely ill and disabled, pain levels went through the roof and ironically ended up with even weaker not stronger muscles. The muscles I use the most are the ones losing bulk and strength.

Name: Karen

I was diagnosed in 1988 by someone who was studying CFS. He warned me back then already that exercise while the virus was active was not beneficial. I proved it to myself that if I did a little too much, even just once, I would get worse.

In 2001-2003, I saw a doctor who clearly knows nothing about CFS. I was assured that if I would exercise I would "feel better" and "have more energy". I tried it for a couple days, and again, felt worse. This guy is now petulantly telling disability that I'm still sick because I won't follow doctor's orders -- he can't accept that I am following some OTHER doctor's orders, not his.

Paul Cheney was interviewed in 2004 about a recent study showing 100% of disabled CFS patients have cardiomyopathy, apparently from the virus settling in the heart, and he made it clear that *fibro* patients improve with exercise (because they don't have this heart condition), but that CFS patients cannot exercise.
In googling to see what (if any) mainstream media exposure that research got, I found a 1998 article saying that Dr. Martin Lerner also found cardiomyopathy, and advises "resting the heart ... to prevent the death of cardiac tissue". This study "explains why patients relapse with exertion".

Just recently, after being reassured by one of the doctors that I'm suing that regular exercise would give me more energy, I decided to try it again, to document the results. Nearly a month later, I'm still in more pain, and instead of having more energy at the end of a week, I had to spend the weekend in bed.

Name: Cindy Country: US

I too was strongly encouraged by physiotherapists to exercise and insurance doctors said worse things to me about malingering etc. I am having serious heart problems now likely due to the excess exercise for a person who has severe illnesses that worsen on exercise. I am housebound and bedbound a lot with worsening conditions.

Name: Douglas [from Invest in ME]

I thought I'd give you an interesting update about what's been going on when I've visited the local ME centre. Last time I was at the centre the doctor was concerned about my heart rate, and thought I may have an underlying condition. He referred me back to my GP, and wrote a letter to ask the GP do some tests to rule out any heart condition. He said I would be seen again in three months for treatment for ME. I went back to my GP, and he booked me in for a resting ECG, with a nurse (although I use that term loosely, as she didn't seem to know what she was doing!) from the practice. As you may know a resting ECG (especially with no input from a cardiologist) is prone to missing most heart conditions, and only lasts less than a minute. The ECG, as you can imagine, came back fine. I should mention that I am glad that nothing has shown up, as I don't need anything to add to my problems. However, the lack of proper investigation has shown the level of interest my GP has in my health!

I have been back to the ME centre now, and looked forward to some treatment for my ME. The doctor checked my heart again, and listened to my updated condition. He then offered me some treatments, saying: '...we take a pragmatic approach to treatments...and offer three...'

I decided to list the treatments for him, and said I wanted something that would actually work, or at least not make me any worse. As you know the centres offer CBT, GET, and adaptive pacing. This is due to the centre working in conjunction with St.Barts hospital in London; being involved in the PACE and FINE trials.

The doctor tried to extol the virtues of GET, at which point I pointed out that he was concerned about my heart rate, and yet he was asking me to increase it through exercise! As you know, there have been many reports, and surveys that point out GET most likely will make ME worse. He did mention that he didn't think I was suitable for psychological treatments, which I thought was a given for anyone suffering with ME.

I did ask the doctor if there was any possibility of seeing a Homeopath, Naturopath, Aromatherapist, Osteopath, Herbalist, or anyone else who could possibly treat my ME. He said that this wouldn't be an option on the NHS.

This is an interesting juxtaposition.

It is common knowledge that CBT and GET are not treatments for ME, and that people with ME learn pacing on their own (pacing is more of a survival technique than a treatment). There is no possibility of receiving any treatments that may do some good (probably because they are natural treatments, and are shunned by the health authorities), and so where does this leave me? I refuse to be subjected to treatments that will make me worse, and I am refused treatments that may ease my symptoms. So the situation is this: I am (and have been) faced with a GP who is not interested in my health, and is rude and condescending. I have not received proper tests to determine my condition, and any additional complications. I have waited for over a year to be treated, and the only things I have been offered have been proven to be detrimental to my health. I have never been given any support or help by the medical profession, and have had to do their jobs for them; in finding out what I may have, and researching ME and possible treatments. I am left hoping that I may be able to be a test subject for a treatment (funded through charity, and nothing to do with the NHS) that I am so desperate for, I am willing to try anything that may work. If I cannot become involved with any trials that may occur, I am at a loss to know where to turn next. It is clear that hundreds of thousands of people are in the same situation as me, faced with no hope, no help, and uninterested medical professionals (I use the term loosely). It is also abundantly clear that the government has no interest in the people they are supposed to serve.
This is a telling lesson for anyone who thinks that their health is important to anyone but themselves, and that no matter what you do or if you try, no one cares.

Name: jundanj2* [Online]

Graded" Exercise Some days I can do more than others. Sometimes what I did 2 days ago puts me in bed today. I don't feel it's a positive since it only makes PWC's feel worse--mentally and physically.

Name: taxdoc* [Online]

Kept crashing.

Name: Claire [Online]

I attended a Cognitive Behaviour Therapist on the NHS as I asked about Gradiated Exercise. Sorry did nothing for my physical well being and not much for my mental state. I have always had the determination to go for it and will happily burn out doing exercise for the mental buzz of being back to normal for that instance. Daft idea, don't do it, you only regret it after (for days), listen to your body. No-one else can tell you if you [are well enough] for it at this moment in time. Cognitive Behaviour Therapy got me hooked on an unrealistic exercise dream it didn't take into account needing to walk to the nearby shop for milk (did this count as part my exercise time - I never felt so) or a bad nights sleep. It wasn't for me and while I'd love someone else to be in charge and say do this and all will be well my body does it's best to tell me if only I listened more.

Name: Angie [Online]

I have been working with graded walking as an exercise treatment for my CFS for 18 months now. I do not find it very helpfull at all. It does keep me moving and thereforo I suppose keeps my joints from seizing right up but the exhaustion, malaise and worsening of other symptoms from the exercise make me question whether or not it is tryly worth the extraordinary effor needed to actually do it.

Name: Pauline [Online]

Tried a 10 minute walk. Loved the walk, however there is always a price to pay with CFIDS. By the next day, I was in terrible pain, and the additional, extreme exhaustion lasted two weeks.

Increasing exercise, even in times when I was quite well has always had bad effects. Had I only known that I had CFIDS some 20 years ago, I would have been a lot more careful about exercise. I never recovered from my last exercise, February 1998. Thanks to Dear Abby's second publication giving the details of this dreadful syndrome, I finally knew what I had. A little too late to helm me. Never rebounded and with each year becomes noticeab.

Name: Suzy [from Invest in ME]

‘A nasty deterioration started to set in quickly. Apart from other worsening problems that Suzy began to experience, she found herself needing to lie down for most of the day since any activity, physical or mental, was becoming impossible.

Less than a year on from the start of this bad deterioration, the illness turned into a nightmare of the worst kind.

The months dragged by. For the first two years they saw Suzanne deteriorating in her bed-bound existence, often unable to communicate (let alone hold a spoon) even by blinking or finger movement.

By the time 8 months had passed Suzanne could only manage to wake up for about 2 or 3 ten minute periods----- if we were lucky ----- out of each of the two separate hours in the day we chose to try and wake her. In order for this to happen Mum or Dad had to spend 3 hours sitting quite still and silent in the cold dark beside her bed.

Eventually (making it sound much simpler than the choice actually was) we decided to reduce this procedure to
just once a day instead of twice, and to aim for one hour of time awake for Suzy between 7 and 8 in the evenings.

As before, Suzy would only wake up after Mum or Dad had sat beside her bed for 3 hours gently trying, very occasionally, to coax her out of her comatose state.

We gradually reduced this 3 hour period, but it took over 18 months (until around June 2004) of painfully slow improvement in Suzy's state, for us to dispense with it altogether.

Suzy's motivation for waking had always been that she was desperate to try to eat (even though this wasn't always possible), as she was so fearful of being tube fed as we were told must be the case----- just as she begged us not to let her be hospitalised, as this was also something we were facing.

(It's only by understanding gained from living with this condition that our desperation to keep our daughter at home could be understood.)

Suzy was in a "living death" state for the first two years after her illness became really severe. Many would still regard her as such since her condition remains very sad.

Even up to around October 2004, two people in the room or one person stringing more than three sentences together was too much for her. Thankfully, things in this respect have now improved. Though the two people are still mostly restricted to Mum and Dad, wonderful exceptions have begun to happen recently for 10 - 15 minutes later in the day.

Suzy's life was, and still is (except for her fans no longer being continually on), spent in a perpetually darkened, unheated, noise-free room. There are blankets over the curtains---- despite it being a north facing room; bedside fans are periodically on---- even though she only wears thin short-sleeved T-shirts all year round and; ear plugs in---- even though the room is in a very quiet location). (…)

There is a positive movement---- albeit inconsistent---- undoubtedly happening in Suzy's condition. In fact recently it is happening relatively quickly. We are just so frightened of when and where it might stop.

We feel this improvement has emerged because of our developing confidence in being able to reject [psychiatrically based] medical approaches to Suzy's severe ME, and to the departures we chose to make from these treatments. (…)

2. We were certain that the graded exercise program Suzy followed in the early stages of her ME was a big mistake. We had no hesitation in no longer sticking to any kind of graded exercise routine. Instead we took the approach of letting Suzy do what she felt she could do----- which for nearly two years was nothing at all. This is a second option we are convinced we made the right choice over.

3. Stopping the involvement of psychologists

A third decision we know to have been the right decision, was to stop the involvement of psychologists in an illness we are convinced is not psychological.'

Name: Emma [from Invest in ME]

This was the second paediatrician I had spoken to, the first wanted to repeat all the blood tests from a few weeks before, and was suggesting anti-depressants and a hospital stay before he'd even seen her. Emma was now so noise sensitive that I couldn't listen to the radio at home and the thrice-daily playtime at the nearby school would reduce her to tears. She was also very light sensitive and had the curtains permanently drawn. Bright lights or sunshine made her to weep with pain. Hospital would be agonising.

We borrowed a wheelchair from the Red Cross, bless them, to get to appointments, and to escape from the flat we went out using my new toy, a bat detector. Fortunately there was a roost just up the road that was accessible by wheelchair and bats like it quiet and dark too.

Some time around May or June 2003 I got a letter from social services asking me to contact them. In my innocence I thought it was a follow up to our claim for DLA (Disability Living Allowance), so from the disability team offering support. Not a bit of it, my sister had reported me for suspected Munchausen's by Proxy. The fact that she hadn't seen us for two years hadn't held her back. So to add to the difficulties of dealing with the school, the benefits system, a paediatrician from hell and a sick child, I now had to deal with a social services investigation. Fortunately, I laughed it off and suggested they check their files - we'd been there before when I
wouldn't play ball with my dysfunctional family and that social worker had decided that I deserved sympathy: she found my family overbearing. I heard no more about the investigation, just silence. But it meant that I felt as if I couldn't contact Social Services for support in case I reopened that particular can of worms.

We also had a visit from the medical examiner from DLA. I'd read such horror stories of DLA being turned down that I pushed Emma to overdo it the day before so he could see how ill she really was. It was a mistake. She was back to having full body spasms, having to be held down on the bed so that she didn't involuntarily flick herself off on to the floor. It also took weeks to recover.

Another little humiliation was the monthly visit from the Educational Welfare Officer. He was pleasant enough, but the permanent checking up by officialdom was not. It also used energy better spent constructively.

This isn't all doom and gloom. Now, in April 2005, my daughter is much better and is doing her best to "pass as normal" at college. She's attending part time, taking 3 AS levels to add to the 5 GCSEs she passed well last summer. It has taken all this time inching forward to get this far, including over a year using a wheelchair. We passed on the GET (graded exercise therapy) and CBT (cognitive behaviour therapy), which was all that was on offer and relied on pacing and diet as treatment - going it alone.

A PERSONAL STORY-SHEILA BARRY [Online]

‘You will have heard, or you will hear, from people who are very qualified to speak here - I regard myself as an ordinary mother but then nothing is ordinary if you have an ME sufferer in the family. So why have I travelled down from York to speak at this book launch. I am here to tell you of the devastating effect the situation outlined in this book, has on the lives of ME sufferers. Skewed clearly outlines the reasons why many of those suffering from ME feel alone, isolated and have little hope for the future.

I personally regard psychiatry as a growth industry. The number of conditions identified as mental illness has grown tremendously in recent years. MS and Parkinson's, among others, were earlier identified as psychiatric illnesses and recently I read that 'shyness' has been classified as a psychiatric condition. How do they arrive at these decisions.

Psychiatrists classify a condition when a number of them are able to agree a criteria. They have no diagnostic tests. It is simply a matter of opinion.

I believe that the actions of the psychiatric lobby to have ME classified as a psychiatric illness and to prevent research into the cause, and a diagnostic test were the major reason that my daughter chose to end her life.’

SURVEYS ON PEOPLE WITH M.E. ON CBT AND GET:

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

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

SOME FACTS AND FIGURES ON CBT, GET AND OTHER APPROACHES Directly from the 'Horses' Mouths: written 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. The aim was to find out what really worked in treating these conditions and based on findings, to then compile Guidelines on Diagnosis and Treatment for Clinicians and other Health Care Professionals.

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

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. One thing is certain: psychiatrists have made things worse for many, in more ways than one.

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Comments from Greg Crowhurst of the 25% M.E. Group to the Gibson Enquiry: including comments from 25% members, December 2005

Includes comments from 25% members on CBT, GET and the effect of the ‘psychiatric’ approach to M.E.

“This will be revealed as one of the biggest medical scandals in history” declared a severe ME sufferer. This Report, based on an email survey of sixty-four severely ill, classical, Ramsay-defined ME/CFS sufferers, with a “multiplicity of symptoms” including, muscle phenomena, circulatory impairment and cerebral dysfunction (Ramsay 1988), was conducted at short notice in December 2005 especially for the Parliamentary Inquiry, by the 25% Severe ME Group.

‘When I was first ill (8 years ago) my condition started to improve a little and my GP suggested I get back to exercising. It wasn’t really graded exercise – he said I should ‘get on my bike and get my heart pumping again.” I did this along with some aerobic exercise thinking this would get my fitness back. I then became severely affected and have been for the past 8 years.’

‘After I came home from the hospital where I received CBT/GET therapy, a physio came to see me once a week. The first one was absolutely appalling, and used to drag me up off the bed and hold me upright, even though I was too ill to cope with this, and my body was collapsing under me. It was a ‘fight’ really, with her believing that if I wasn’t allowed to sit down, the muscles in my legs would improve, and I would gradually begin to weight-bear’

Crowhurst comments: Sufferers are far too ill to protest, and too ill to ever undergo the so called behavioural remedies being developed in their name, but will never successfully treat anyone with real ME, as one sufferer explains:

“I have been ill in different phases for 15 years. I have worked it out for myself that you can only “exercise” within very narrow limits. It is simply not the case that you can exercise your way out of this illness. If it were that simple most people with ME who were previously very fit and active, would have long since recovered.”

Often the only choice for sufferers is to avoid the medical profession, because of its negative attitudes and inappropriate, negative treatment, as one sufferer describes:

I participated in Graded Exercise therapy via the ‘National M.E Centre’, Romford, Essex. This lead to a relapse, at home, and made me unable to sit upright for 1 year due to pressure in my head, and chest pain. I then relapsed and ended up in my local NHS Hospital in a cardiac care unit.

Another sufferer describes how, despite an “extensive psychiatric evaluation” which resulted in a report saying ‘she is severely physically disabled’, ‘has no mood or behavioural problems’ and ‘is coping remarkably well given very difficult circumstances’, she was still offered “CBT and counselling and my symptoms of severe nerve pain, nausea, difficulties with speaking, sight, swallowing and eating, seizure like brain activity, intermittent paralysis, contractures in hands and feet etc were left un-investigated and untreated.”
This sufferer states how: “I could see the sense in graded exercise and how it could help someone to comeback from an illness and aid in their recovery but unfortunately with ME this treatment does not work and just sets you back”.

“If you do not respond to Graded Activity, the Benefits Agency seem to think you are either malingering or depressed and benefits are refused. The Agency, and in particular their Medical Examiners, seem oblivious to the problems and symptoms of severe ME and all seem under the impression that everyone with ME recovers in under 5 years. If you are still ill after that it either isn’t ME or you are mentally or behaviourally ill in some way.”

Just how dangerous aerobic exercise can be for the severe ME sufferer is illustrated by this respondent’s tragic story

“I was an in-patient in a psychiatric ward of a London hospital. I was the only patient who did not have a mental health problem, and although my CBT therapist had had plenty of experience of working with M.E. patients, I was the first to be admitted as an in-patient. I only saw my therapist once a week, and the psychiatric nurses had no understanding of my illness at all. There was a huge amount of stress, and I was treated very badly by some of them. I received both CBT and GET, but the graded exercise seemed to be given priority. I worked with a physiotherapist, who also had no experience of M.E. I began to seriously deteriorate, and 4 months in, suffered a major relapse. I had a kind of undiagnosed ‘stroke’, collapsed, and became incapable of looking after myself. When I went to the hospital I could walk 100 yd., feed, wash and dress myself. When I left I could not weight bear at all, had no leg muscles to speak of, and needed two people to transfer me on and off the toilet and in and out of bed. I had little use of my hands and was totally bed bound. I could not tolerate sitting upright against the pillows, conversation was beyond me, and I could barely manage to feed myself by picking up food in my hands - cutlery was out of the question. Nine years later I have improved, but I'm still bed bound”.

Another sufferer tells how: “I am not monitored by anyone. I only see my GP if I have an unrelated problem, eg. a chest infection or need an alteration to my existing drugs. I have not been seen by a consultant for 8 years. I have never been seen by anyone specialising in ME, apart from a psychiatrist whom I do not accept as an ME specialist as my illness is not a mental health or behaviour problem.”

Conclusion

This report paints a desperate picture. Surely our respondent was right to call this a “medical scandal” of gross proportions.

Despite the real danger of Graded Exercise Therapy being harmful to the severely affected, 44% of respondents were still offered this intervention.

Every survey of sufferers (and this one is no exception) seriously calls into question the efficacy of GET and CBT: 96% and 95% respectively of respondents who tried it said that it had a negative impact upon their symptoms, yet as this report shows, this is often the only “treatment” on offer to sufferers and is the one being vigorously pursued by Government.

Significantly more than half of those offered CBT or GET refused the treatment; that is because, as the study has shown, people are very aware and are simply not willing to be made worse. However the bleak reality is that more than half of sufferers, each one on average experiencing more than 20 severe neurological, autonomic and endocrine symptoms, are just being left to get on with it, with no treatment whatsoever, some for decades.

This report has presented shocking evidence of abuse at the hands of the psychiatric lobby. Our members have reported being locked in secure psychiatric wards or AIDS units and their lack of response to “treatment” being taken as an indication of their misguided thinking.

It is time to acknowledge and address the main issues underlying the reasons for this abuse.

Click here to read the entire document; many more quotes from severe M.E. sufferers are given in the text, as well as some high quality medical information, this text is highly recommended

NOTE: An * denotes that a name has been changed by request for the protection of privacy.
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 some 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 misrepresented 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

Reference list:


93. Williams, Margaret 2003, Quotations from "SOMATIC MEDICINE ABUSES PSYCHIATRY - AND NEGLECTS CAUSAL RESEARCH" by Per Dalen [Online], Available: http://www.hfme.org/wmarshallandwilliams.htm

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