

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

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

### **Who benefits from 'CFS' and 'ME/CFS'?**

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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?

The short and simple answer to this question is: medical insurance companies.

Medical insurance companies were heavily involved in the creation of 'CFS' and they remain heavily involved in the promotion and dominance of the 'CFS' concept today. M.E. is a widespread problem, potentially exposing medical insurance companies to the financial risk of huge numbers of long-term disability claims. Through the creation of the bogus disease category of 'CFS' these companies have saved themselves many millions of dollars. They have been able to deny many thousands of legitimate claims. The 'CFS' concept has saved an incredible amount of money for these companies. This is why 'CFS' is proving so resistant to scientific reality, despite pressure from patient groups who are trying to stop the horrific abuse and needless deaths caused by the 'CFS' scam: because such enormous amounts of money are at stake these medical insurance companies will stop at nothing to protect their enormous financial gains.

The problem is *not* a lack of scientific evidence supporting M.E., but that the mountain of evidence which exists is continually ignored by those in positions of power who are abusing that power to further their own vested interests, helped immeasurably by the creation of 'CFS.' For 20 years this massive scientific fraud has continued almost unchallenged by the world's media, human rights groups and governments. It is a worldwide disgrace. The bogus and financially motivated disease category of 'CFS' must be abandoned.

For more information on this topic, and details on some of the other vested groups involved, please read on. Sections in this paper include the following:

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## 1. Where did the artificial 'CFS' construct come from?

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

The new name and case definition for 'CFS' was created in the US in 1988 by a board of 18 members, few of whom had either looked at an epidemic of M.E. or examined any patients with M.E. Two of the most experienced members of the board refused to sign the final document and withdrew 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]).

The UK definition of 'CFS' was also arrived at without the vast majority of those involved having had the benefit of examining either individual patients *or* an outbreak of the illness. Many of them were also psychologists or psychiatrists rather than physicians. It was a similar story worldwide. As M.E. expert Dr Byron Hyde writes, 'The inclusion of psychiatrists in the defining of an epidemic and [what is] obviously a disease of infectious origin, simply muddies the water for any serious understanding of that disease' (1998, [Online]).

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 are of primary importance. *The distinction must be made between terminology and definitions.* To summarise:

**Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.

**Myalgic Encephalomyelitis** is a debilitating 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. It can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934. M.E. 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. is incorrect.

The distinct neurological disease known since 1956 as Myalgic Encephalomyelitis has a similar strike rate to multiple sclerosis. M.E. can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares significant similarities with multiple sclerosis (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 or even essential symptom of M.E. People with M.E. would give anything to be only severely 'fatigued' instead of having M.E.

## 2. Who benefits from the artificial 'CFS' construct?

**A. Medical insurance companies.** Why were the renaming and redefining of the distinct neurological disease Myalgic Encephalomyelitis allowed – indeed intended – to become so muddled? 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] (2003a, [Online]). 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 (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. (These inappropriate interventions are at best useless and at worst extremely harmful or fatal for M.E. patients. See Smoke and mirrors and What is M.E.? Extra extended version.)

'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 goes on to say 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]).

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:

**B. Governments around the world.** Governments around the world are undoubtedly complicit in the M.E. cover-up and the 'CFS' scam. Governments have not served the interests of their people. The public has been sold out by governments protecting their own interests and those of their allies in industry and big business. Governments have saved money by failing to support M.E. patients in three distinct areas:

- I. **Research:** instead of the appropriate levels of funding for biomedical research on M.E. (similar to levels spent on diseases which are less devastating), governments make huge savings by spending small amounts of money on useless 'CFS' research involving mixed patients groups.
- II. **Welfare:** the rightful welfare claims of M.E. patients have frequently been denied. In many countries where disabled patients who are unable to work are in theory eligible for welfare payments, in practice the welfare system makes it very difficult for a patient with M.E. to qualify. Even if a claim is successful, the system may incorrectly categorise the M.E. patient as suffering from 'CFS' and so a primarily psychological illness; in the UK, for example, a lower rate of welfare payments are made for those deemed to suffer from psychological illnesses.
- III. **Medical care:** in those countries where health care is in theory available to all, because government policy does not recognise M.E., appropriate medical care is not available for M.E. patients. For example, appropriate brain scans, other neurological testing and cardiac function testing are not routinely offered to M.E. patients. In addition, severely disabled M.E. patients may not receive even the most basic medical care. These patients are bedbound and housebound and unable to visit the doctor, and may not be successful in obtaining home visits from doctors who are not knowledgeable about M.E.

If the truth were to become widely known, governments would have to explain to voters why they had participated in this cover-up, involving such horrific and systemic abuse and neglect of M.E. patients. They would also have to explain why they have so freely declared many potentially dangerous chemicals legal and safe, despite a lack of proper testing. They would also have to explain why they have not held the vaccine industry to account for its role in the rise of M.E. They would also have to explain why they did not protect the blood supply from M.E. infected blood, and why they did nothing to halt the spread of M.E. through blood transfusions. Lawsuits would result if these matters were widely known, which might explain why governments are so committed to the 'CFS' cover-up.

The CDC in the USA in particular has a lot to lose. Having created and promoted the 'CFS' scam, it would lose all authority and credibility if this finally becomes widely known by the public.

(In addition, the mission of the CDC, why it was created, was to combat infectious diseases such as polio. Polio was becoming a huge problem at the time. The CDC studied polio comprehensively, and oversaw the polio vaccine program. So the CDC also benefits enormously from the clear links between M.E., polio and the polio vaccine staying hidden from the public. The CDC are implicated in the 'CFS' scam in a number of serious ways. They may even be the primary force behind the 'CFS' scam and the cover-up of M.E.)

**Governments lose out in the long term by participating in the 'CFS' scam, unlike corporate interests which benefit.** For corporate interests the scam is win/win (so long as it remains hidden from most of the public) but for governments the losses end up outweighing the savings. Patients who do not receive basic medical care and advice in the early stages of their illness may be prevented for far longer than necessary from re-entering the workforce. With early support patients may only need a short period off work to regain (some of) their health, whereas without early support they may become so ill that they have to rely on welfare for decades. Some may become permanently disabled and require lifelong welfare support.

There is an immense human cost as well as the financial cost of government policies.

All of the patients misdiagnosed with 'CFS' are denied a correct diagnosis and so appropriate care and treatment, and so this also adds to the number of people on welfare who would otherwise, if not for the 'CFS' scam, be able to be treated and to work full-time again. Many of the diseases misdiagnosed as 'CFS' are very treatable, but ONLY once correctly diagnosed.

The community loses too by so many valuable members being far more ill than they need to be and so unable to participate fully in the community. It is also true that some patients may die due to lack of appropriate care.

Millions of dollars have also been wasted studying the effects of CBT and GET (etc.) on mixed fatigue groups. Research that has been set up by those with vested interests and is extremely unlikely to help any patient groups or produce any valid or useful information. All 'CFS' government research is a complete waste of money as there are mixed patient groups involved, not to mention the lack of scientific integrity in the way these studies are carefully conducted to show results favourable to vested interest groups.

The way government has pushed inappropriate treatments such as CBT and GET on M.E. patients has harmed the patients severely and made them even more in need of extensive medical care and time off work. Those governments that most aggressively collude with insurance companies to push inappropriate treatments onto patients such as CBT and GET are generally those in countries where disability costs are born largely by government, rather than insurance companies (eg. the UK and Australia). In countries where disability costs are paid primarily by insurance companies (eg. the US), the treatment of patients is currently largely ignored by government (for now at least – though the system in these countries may change in future). The approach taken depends primarily on the governments 'bottom line.'

**C. The vaccine industry.** The rise of M.E. coincided with the distribution of the polio vaccine and experts believe the two events are linked. The vaccine industry has participated in the cover-up of this information and about the facts of M.E. If it were to become known that vaccines are involved in such a severely disabling neurological disease, large financial losses would likely be incurred by the vaccine industry. The polio vaccine is touted time and time again as the model for vaccine success, and as something to aim for with other diseases. The polio vaccine is put on a pedestal as representing vaccine science at its best. If it turns out this idea is seriously flawed, and that the polio vaccine has significant drawbacks and has caused severe and widespread harm, there would be large financial losses and legal challenges. The validity of the entire vaccine industry might be put in question.

**D. The chemical industry.** Some of the diseases misdiagnosed as 'CFS' are clearly caused by exposure to chemicals. M.E. can also predispose patients to later chemical injury due to the damage to the brain stem, disruption of the blood brain barrier, damage to detoxification systems, microcirculatory damage, and so on (which may then be mistaken as the primary cause of the illness). The chemical industry has participated in the cover-up of this information and about the facts of M.E. If it were to become known that common legal chemicals are involved in causing severe disease and exacerbating diseases such as M.E. for example, large financial losses would likely be incurred by the chemical industry.

**E. The profession of psychiatry.** The role of psychiatrists in creating and promoting 'CFS,' in collaboration with the medical insurance industry, has been discussed in section A above. Psychiatrists and other mental health workers have a vested interest in not admitting that they were wrong or that they acted unethically. These groups would lose credibility and respect by having to admit that they were either incredibly stupid to miss the truth about 'CFS' or that they had been guided by financial and political interests rather than hard facts and ethics. If the truth about 'CFS' and M.E. were to become known, some of these individuals may also face serious lawsuits and even lose their careers. The profession of psychiatry itself would also drastically lose credibility.

**F. 'CFS' doctors who have made a career out of being 'CFS' experts.** Some of these individuals are given a lot of praise, respect and power by patients. These individuals would lose their positions and respect if it were to become known that 'CFS' doesn't exist and that all along they had been merely benefiting themselves, working against the best interests of patients. Their reputations would be destroyed. In some cases financial benefits would also be lost, especially with those doctors who sell large numbers of 'CFS' books promising to leave very tired people feeling 'fantastic!' or who have made a name for themselves with TV appearances on this topic.

**G. Medical doctors.** GPs and other health workers have a vested interest in not having to admit that they were wrong or that they have acted unethically. These groups would lose credibility and respect by having to admit that they were either incredibly stupid to miss the truth about 'CFS' or that they had been guided by financial and political vested interests rather than hard facts and ethics. If the truth about 'CFS' and M.E. were to become known, some of these individuals may also face serious lawsuits and even lose their careers.

**H. The media, including medical journals who have sold out science to 'CFS'.** These groups would lose credibility and respect by having to admit that they were either incredibly stupid to miss the truth about 'CFS' or that they had been guided by financial and political vested interests rather than hard facts and ethics. They have a vested interest in not having to admit that they were wrong or acted unethically. That they did so is clearly shown by their actions.

**I. 'CFS' or 'ME/CFS' etc. groups that sell vitamins and other supplements to those patients misdiagnosed with 'CFS' and so on.** Sales would decline rapidly if these 'CFS' misdiagnosed patients were given correct diagnosis and treatment and were not to desperate to spend all that they had on supplements. There may also be other perks these groups would lose by no longer being in the position of selling out to big business and government.

**J. CFS' and 'ME/CFS' (etc.) so-called patient support and advocacy groups.** Some of these individuals and groups are given a lot of praise, respect and power by patients. Groups would lose their members. These groups and individuals would lose their positions and respect if it were to become known that 'CFS' doesn't exist and that they had been working all along against the best interests of patients. In some cases financial benefits for the groups and individual would also be lost. There may also be perks these groups and individuals would lose by no longer being in the position of selling out to big business and government. Successful careers and prestige would be lost. Reputations would be destroyed.

The vast majority of CFS, ME/CFS, CFS/ME, ME-CFS, CFIDS and Myalgic Encephalopathy advocacy groups (or whatever other term they're using, including Myalgic Encephalomyelitis) in Australia, the UK, the US, the Netherlands and all around the world are not involved in legitimate or useful advocacy. Most such groups have sold us out to the highest bidder. These groups benefit, either in terms of funding, influence or in other ways, by following government policy and by their association with corporate vested interests. We have to wake up to the reality, as distressing as it is. This includes groups such as AfME and the MEA in the UK, the ME/Chronic Fatigue Syndrome Society of Victoria in Australia (and most of the other Australian 'CFS/ME' or 'ME/CFS' groups), and the CFIDS Association of America (CAA), among many others. These groups are not helping ANYONE, except themselves, and the vested interest groups who profit from 'CFS.'

Because of these groups, most people with M.E. have no idea about even the most basic facts about M.E. or the history of M.E. and no progress has been made at all as regards M.E. advocacy for 20 years. We must demand more of 'our' groups if we want to get anywhere.

A big problem is that many patients cling to 'CFS' because it's the only diagnosis they've got, and they think it protects them. It's understandable that these patients want their illness to be taken seriously, but the diagnosis of 'CFS' does them a disservice because what they really need is accurate diagnosis so that their illness can be properly addressed. Another big problem is that some patients with a 'CFS' diagnosis support the concept of 'ME/CFS' because they believe that the 'M.E. part of the composite term brings them closer to a diagnosis of M.E. But as this is an incorrect diagnosis for the vast majority of 'CFS' diagnosed patients, this only increases the unethical obfuscation that benefits vested interest groups. ME/CFS' harms all patients and patient groups involved and makes a mockery of genuine advocacy.

- For more information please see: [Problems with 'our' M.E. \(or 'CFS' 'CFIDS' or 'ME/CFS' etc.\) advocacy groups](#) 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.](#) See also: [Are we just 'marking time'?](#)

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

The creation of the bogus disease category 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various unrelated psychiatric fatigue states, post-viral syndromes and other fatigue states for the benefit of various proven financial and political interests

The resulting 'confusion' between the distinct neurological disease M.E. and the artificial disease category of 'CFS' has caused an overwhelming additional burden of suffering for those who suffer from neurological M.E. and their families. **It's a big huge mess, that is for certain – but it is not an accidental mess – that is for certain too** (Hyde 2006a, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]).

It is also a certainty that the 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

#### **4. But aren't alternate concepts such as 'ME/CFS, Myalgic 'Encephalopathy' and 'CFIDS' at least an improvement on 'CFS'?**

No, they are not. Most often when the term 'ME/CFS' is used, it refers to a bizarre mix of facts relating to both M.E. and 'CFS' or instead purely facts relating to any of the various bogus 'CFS' definitions. The same applies to the terms 'CFS/ME,' 'CFIDS' and 'Myalgic Encephalopathy.'

**A. 'ME/CFS' and 'CFS/ME.'** The groups that benefit from 'ME/CFS' are the same groups that benefit from 'CFS.' It is hardly a coincidence that Professor Simon Wessely – the most powerful and influential of the group of doctors who have made themselves the tools of insurance companies – is the person credited with inventing the mixed term 'CFS/ME.' The mixing of M.E. and 'CFS' into 'CFS/ME' or 'ME/CFS' serves vested interest groups well. This is why so many of the very worst government reports (and so on) in the UK, Australia and the Netherlands which talk about patients as if they were mildly ill malingerers who could easily improve if not recover from their 'fatigue' if only they could be convinced to try CBT or GET, and so on, (a) often use terms such as 'CFS/ME' or 'ME/CFS' in the titles and throughout and (b) very often mix in some of the facts about M.E. (i.e. symptoms, history, severity/disability etc.) with bogus information about 'CFS' while of course the entirety of the all-important CONCLUSIONS given (i.e. aetiology, psychological status, improvement of symptoms, response to treatments and recovery rates) is drawn exclusively from non-M.E. patient groups, and from the most mildly affected physically and the most primarily psychologically ill members of these 'CFS' diagnosed groups.

'ME/CFS' and 'CFS/ME' lets these vested interest groups have it both ways. They get to continue happily with their unscientific and unethical 'CFS' obfuscation agenda, which allows governments and insurance companies to deny medical and welfare claims, and they get to do so with far less opposition from the patients they're harming, or even with the support of some of these patients and patient groups who are taken in by the superficial appearance of progress conferred by a mere terminology mix.

This is why 'ME/CFS' articles and studies are even more dangerous in many ways than pure 'psychological CFS' ones. The issue is not that 'ME/CFS' just isn't a very good solution that will not do much good, as many have been arguing. There is so much more than that at stake here. Not only will 'ME/CFS' not help, it can and will make things so much worse. It will make the truth about M.E. even more invisible (or 'inaccessible') by hiding it in plain sight. make it harder than ever for anyone to separate M.E. out from the vague mess of 'CFS' or for those misdiagnosed as 'CFS' to be receive a correct diagnosis and appropriate treatment, as is their basic right.

The 'ME/CFS' concept is confusing, illogical, strongly reinforces the same misinformation which is the cause of the problem (i.e. that M.E. and 'CFS' are the same and that 'CFS' actually exists), and holds back the fight for justice and recognition of authentic neurological Myalgic Encephalomyelitis immeasurably. The mixing of M.E. and 'CFS' was invented by these vested interest groups and it is a tool they use to good effect and as much as possible. The countries in which the 'ME/CFS' concept is commonplace are those in which patients are subject to the most shocking abuse, far worse than that which occurs now in the US.

For information on the sort of extreme abuse of 'ME/CFS' or 'CFS' patients which occurs in the UK and the Netherlands and to a lesser extent in Australia – including ill children being forcibly removed from their homes, children being thrown in swimming pools or denied food or family contact to uncover their 'faked' symptoms, forced exercise and CBT programs which have led to severe disability and even death, and people being illegally sectioned or classified as unfit under the Mental Health Act (with consequent loss of rights), and so on – please see: [What is M.E.? Extra extended version.](#)

None of the justifications made by so-called advocacy groups for using the term 'ME/CFS' hold up. Putting M.E. together with 'CFS' doesn't add to the credibility of 'CFS' – it just strips M.E. of credibility and scientific legitimacy – which indeed seems to be the entire point of the exercise.

- For more information on why advocates and patients must reject 'ME/CFS' see: [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.](#)

**B. Myalgic 'Encephalopathy.'** Myalgic 'Encephalopathy' is a made-up term that was created only *after* the disastrous 'CFS' definitions. The term Myalgic 'Encephalopathy' was created in the UK, for reasons involving politics and vested interests rather than science. The claimed scientific justifications for the creation and use of this made-up name are bogus. Myalgic 'Encephalopathy' is linked to no specific definition and no specific patient group. The term was not created through a careful examination of the evidence or because of any specific research findings. There is no scientific evidence behind ME'opathy whatsoever and (as is appropriate) this term has no WHO ICD classification. ME'opathy is merely another name for 'CFS.' It is a term that could be taken to mean anything and so is just as meaningless *and as harmful* as 'CFS' is.

Do not be fooled by the merely superficial similarity of these terms – Myalgic Encephalomyelitis is not at all the same thing as Myalgic 'Encephalopathy.' Patients with authentic M.E. do have the damage to the brain referred to in the name Myalgic Encephalomyelitis; however this damage is of course not found in patients suffering various types of chronic fatigue illnesses which are commonly misdiagnosed as 'CFS.' Legitimate M.E. experts, advocates and researchers do not support the name change from Myalgic Encephalomyelitis to Myalgic 'Encephalopathy.' Patient advocates [Margaret Williams and Eileen Marshall](#) write:

Despite the relentless financial, psychosocial and political engineering that seems to underpin the current determination to remove the term "myalgic encephalomyelitis" (M.E.) from the medical lexicon (where, based on accurate published evidence of the nature of the disorder, it has resided for the last half century), the present proponents of its demise have failed to produce any evidence-base to support their clamour for its removal and its replacement by the less specific term "myalgic encephalopathy" (2004a, [Online])

Support for this term is red flag that lets you know a group is not to be trusted and is not involved in genuine advocacy. The use of the meaningless term Myalgic 'Encephalopathy' is a dishonest attempt to divest Myalgic Encephalomyelitis of the legitimacy and protection of its correct WHO classification. It is also an attempt to cover up the links between M.E., polio and the polio vaccine indicated by the term 'Encephalomyelitis'; to try to hide the 'smoking gun' of the term M.E. as it were. The term 'Myalgic Encephalopathy' is a political creation with no scientific validity, just as 'CFS' is. *It is a trap, a trick.* The last thing needed is yet another vague and ill-defined umbrella term that can easily be manipulated by vested interest groups. As [Professor Malcolm Hooper](#) explains:

There have been persistent and frequently covert attempts by these [vested interest] psychiatrists to subvert the international classification of this disorder, with destructive consequences for those affected. Correct classification does matter because it impacts on correct referral to an appropriate specialist, correct investigations, correct diagnosis, correct management and / or treatment, correct State benefit support [and] correct insurance policy payments (2003a, [Online]) (Hooper & Marshall 2005a, [Online]).

- For more information on the name Myalgic Encephalomyelitis (and the political motivations behind terms such as ME'opathy) see: [On the name MEitis 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'](#)

**C. 'Chronic Fatigue and Immune Dysfunction Syndrome' – 'CFIDS.'** When this term was first used, it was used in some ways as a synonymous term for M.E., but this is no longer the case. Although the end result is the same however, the term 'CFIDS' in contrast with the term Myalgic 'Encephalopathy' was at least well intentioned and a genuine attempt at differentiating those who merely qualify for a 'CFS' misdiagnosis and genuine epidemic and sporadic M.E. patients. Today this term is also just another term used to describe 'CFS' for the most part. The

term 'CFIDS' should in no way be considered as synonymous with M.E. This term is unhelpful and unscientific and only adds to and aids the obfuscation by vested interest groups.

### 5. But isn't the name 'CFS' a big part of the problem?

The reason so many patients are ridiculed, sneered at, belittled, disbelieved, accused of exaggerating or malingering or laziness by medical staff and by friends and family members etc. IS NOT BECAUSE OF THE NAME 'Chronic Fatigue Syndrome'!

If 'CFS' had instead been given a neutral name, say 'Reeves' syndrome' or 'Holmes' syndrome,' the problems would still be *exactly the same*. Vested interest groups – helped in this task IMMEASURABLY by the creation of the bogus disease category of 'CFS' – would still be flooding the medical, political and media communities with lies and propaganda which could only have the end result of making patients seem utterly pathetic and undeserving of any respect or sympathy.

*What else could anyone think of patients who supposedly have an illness that is mild and short lived, but which some patients pretend is severely disabling because they 'enjoy the sick role'? What else could anyone think about an illness that cannot in any way be proved despite vast sums being spent on tests and must be taken completely on faith. What else could you/anyone think about an illness that has been proven to be psychological or behavioural but where patients would prefer to actually stay ill rather than to admit that they are mentally ill?*

Every media article and government press release about 'CFS' is filled with fictional statements which make it very clear in many different ways that the illness has no scientific validity, and that the patients do not deserve the same respect as other patient groups, but should be treated with contempt. Patients are not merely wrongly categorized as psychologically ill; it is so much more than that. It is persecution; patients are talked about (and lied about) as if they were malingerers and deviants, as if they were beneath contempt and not worthy of even basic respect or medical care, or even any level of kindness or compassion – even from their own friends and family. Whatever 'CFS' had been called, these problems would be EXACTLY THE SAME.

*There is no such disease as 'CFS' and 'CFS' is merely an artificial entity created for the benefit of financial vested interest groups – that is the real problem, not the name 'CFS.'*

The infectious neurological disease known since 1956 as Myalgic Encephalomyelitis already has a historically and medically correct name and definition and WHO classification. We also have clear definitions and names for Fibromyalgia, post-viral fatigue syndromes, PTSD, burnout, Lyme disease, Candida, Adrenal exhaustion, cancer, depression, athletes over-training syndrome and the other illnesses commonly misdiagnosed as 'CFS.'

The only thing that makes any sense is for advocates and patients to fight together to get rid of 'CFS' in name and definition, and to have patients correctly diagnosed with and treated for whichever illnesses they actually have, including M.E., in a scientific and ethical manner – without any self-interested interference by financial vested interest groups.

- For more information see: [Problems with the so-called "Fair name" campaign](#) and [Problems with the use of 'ME/CFS' by M.E. advocates](#).

### 6. 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 is it 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 and the government cover-up of Gulf War Syndrome 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.

### 7. 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. 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.

### 8. More information

- To read more on the vast difference between M.E. and 'CFS' as well as more information on M.E. medically, see: [What is M.E.?](#) or [What is M.E.? Extra extended version.](#)
- For more information on the lack of ethics of various so-called 'advocacy' groups and individual advocates in this field, please see: [Problems with 'our' M.E. \(or 'CFS' 'CFIDS' or 'ME/CFS' etc.\) advocacy groups 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.](#) See also: [M.E. advocacy and 'CFS' advocacy are not the same and My comments about the current \(worrying\) state of Australian ME societies and My comments on the CDC's latest 'CFS' press release.](#)
- If you are a former M.E. advocate who now supports the flawed concept of 'ME/CFS' please read: [Problems with the use of 'ME/CFS' by M.E. advocates.](#)
- See the new paper: [M.E. vs MS: Similarities and differences](#)

- Inappropriate interventions such as CBT and GET are at best useless and at worst extremely harmful for M.E. patients. M.E. patients (including children) may be left wheelchair-bound or bedbound following GET, or needing cardiac care units, and there have also been *deaths*. These inappropriate interventions are not always administered voluntarily and often verbal coercion or force is involved. If any drug caused even a very small percentage of the devastation GET causes in M.E. patients (let alone that is also had a 0% chance of success!) it would be immediately recalled, yet GET is being forced on M.E. patients more and more often and is still claimed by those promoting it to be a safe and effective treatment despite all of the overwhelming evidence to the contrary. See [Smoke and mirrors](#) and [What is M.E.? Extra extended version](#) for more information.
- For more in-depth information 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](#) and [The Nightingale Definition of M.E.](#) by Dr Byron Hyde, and [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, plus [What is ME? What is CFS? Information for Clinicians & Lawyers](#) and [The Mental Health Movement: Persecution of Patients?](#) by Professor Malcolm Hooper and [A Public Statement to Government Health Ministers and an ALERT to citizens worldwide](#), and [Activism Articles](#).
- For more information on why the bogus disease category of 'CFS' must be abandoned for the benefit of all the patient groups involved, (along with the use of other vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'CFIDS' and 'Myalgic Encephalopathy' and others) see: [The misdiagnosis of CFS](#), [Why the disease category of 'CFS' must be abandoned](#) and [What is M.E.? Extra extended version](#).
- To read a complete list of the articles and resources available on the site suitable for different groups – severe M.E. patients, M.E. patients, patients misdiagnosed with 'CFS,' doctors, the media, friends and family of M.E. patients, carers and so on – see the [Information Guides](#) page.

## 9. References

This paper, like all the papers by me (Jodi Bassett) on this site, merely provides a brief summary of some of the most important facts of Myalgic Encephalomyelitis. A list of references to original texts is given at the end of each paper, and these references are very highly recommended as essential additional reading for anyone with a real interest in Myalgic Encephalomyelitis. For further information on the references used on this site, to read the reference list for this paper, see the [References](#) page.

Included below is a list of relevant quotes from some of the original texts.

Hillary Johnson, author of a book which documented the mid-eighties M.E. outbreak in the US (Osler's Web), explains that the name 'CFS' was selected: '[By] a small group of politically motivated and/or poorly informed scientists and doctors who were vastly more concerned about cost to insurance companies and the Social Security Administration than about public health. Their deliberate intention – based on the correspondence they exchanged over a period of months – was to obfuscate the nature of the disease by placing it in the realm of the psychiatric rather than the organic. The harm they have caused is surely one of the greatest tragedies in the history of medicine. ... The Government's choice of names was so inept, in fact, that many observers came to view it as a deliberate effort to defuse the potentially panic-inducing issue of the eruption of a life-altering infectious disease. "CFS" after all, hardly sounded "catching".

'In his second letter to Holmes, on October 29, Cornell's Nathaniel Brown wrote that he wanted to be included on the co-author list in a medical journal. But Brown continued to be preoccupied with the costs that published criteria might pose for health insurance companies. He suggested that Holmes include a disclaimer in the definition alerting doctors that disability claims could not be based on the government's diagnostic criteria. "It might discourage chronic reimbursements for the diagnosis-(i.e. long-term disability)-until more is known," Brown wrote.'

Osler's Web, Hillary Johnson, pp 218 - 219:

### **'M.E. is a clearly defined disease process. CFS by definition has always been a syndrome**

At one of the meetings held to determine the 1994 U.S. Centers for Disease Control and Prevention (CDC) definition of CFS, in response to my question from the floor, Dr. Keiji Fukuda stated that numerous M.E. epidemics he cited the Los Angeles County Hospital epidemic of 1934, the Akureyri outbreak of 1947-48 and the 1955-58 Royal Free Hospitals epidemics-- were definitely not CFS epidemics. Dr. Fukuda was correct.

It is the CFS definitions themselves that give rise to this inaccuracy. Consider the following:

(a) What other physical disease definitions essentially state that if you discover the patient has any physical injury or disease, then the patient does not have the illness CFS? In other words if you have CFS then it does not

result in or cause any major illness. What else could CFS then be but any number of various psychiatric, social, hysterical or mendacious phenomena?

(b) The various CDC administrations dealing with the subject have clearly stated that CFS is a physical, not a psychiatric disease. However, is there any other definition of any physical disease that is not provable by scientific and clinical tests? Only psychiatric diseases are not clearly verifiable by physical and technological tests.

(c) What other physical disease definition requires a six month waiting period before the illness can be diagnosed? Any physician knows that to treat a disease adequately you have to be able to define the disease at its onset and treat it immediately in order to prevent chronic complications from arising. There are simply no other disease definitions that have ever been assembled similar to the CFS definitions.'

**The Nightingale Definition of Myalgic Encephalomyelitis (M.E.)** by Dr Byron Hyde 2006

'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. The CDC definition is not a disease process.'

'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 and the more problematic it becomes.'

**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 Hyde

'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). Although the authors of these definitions have repeatedly stated that they are defining a syndrome and not a specific disease, patient, physician, and insurer alike have tended to treat this syndrome as a specific disease or illness, with at times a potentially specific treatment and a specific outcome. This has resulted in much confusion, and many physicians are now diagnosing CFS as though it were a specific illness.'

'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.'

**The Complexities of Diagnosis** by Byron Hyde MD 2003

'M.E. has already been called the 'Disease of a Thousand Names', yet, in the Spring of 2001, one of the ME Charities has just applied to the Charities Commission for another change. This time, it is from Myalgic Encephalomyelitis to Myalgic Encephalopathy, that is: from muscle pain accompanied by inflammation of the brain and spinal cord to muscle pain and damage to the brain and spinal cord of unknown origin. This clumsy euphemism will not only bloom less sweetly than it's predecessors but does not fit the facts. Moreover, this change will not benefit research nor relieve the confusion and disbelief which blocks access to standard medical care for these patients.'

**A Rose by Any Other Name** by Dr Elizabeth Dowsett

'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!'

**The Late Effects of M.E.** by Dr Elizabeth Dowsett

'In those countries which have adopted mass polio immunisation during the past 30 years, outbreaks of M.E. still continue unabated. Interest in one such epidemic (Lake Tahoe, Nevada USA 1984) misdiagnosed initially as Epstein-Barr Glandular Fever – a Herpes virus infection, led a group of non-clinical scientists active in the field of Herpes virus research and evaluation of drugs, to formulate and tailor a fitting new research definition (Holmes et

al 1988). Attempts to correct this initial "Fatigue" definition in the UK (Sharpe et al 1991) the USA (Fukada et al 1994) and in Australia (Hickie et al 1995) became so inclusive of a heterogeneous population of sufferers from psychiatric and miscellaneous non psychiatric states as to elevate the suggested prevalence by some 250 times. Major mistakes in these definitions include: (i) overlooking the distinguishing encephalitic features of M.E. (ii) elevating "fatigue" (an inescapable accompaniment of normal human existence and of cardiovascular, metabolic malignant, psychiatric, neurological and other disabling conditions) to unreal diagnostic importance among symptoms. (iii) to suggest that M.E. is merely one subgroup amongst this heterogeneous collection of physiological and pathological states, makes thus making any attempt at differential diagnosis between them impossibly expensive to pursue. (iv) to suggest that diagnosis must be delayed for 6 months, vitiates any real attempt at virus investigation, especially among the young.

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.'

**Redefinitions of M.E. - a 20th Century Phenomenon** by Dr Elizabeth Dowsett

'Following successful immunisation against poliomyelitis in the early 1960s and the removal of 3 strains of polio virus from general circulation in the countries concerned, the related non-polio enteroviruses rapidly filled the vacancy. By 1961, the prevalence of diseases (such as viral meningitis) caused by these agents soared to new heights. In the mid 1980s, the incidence of M.E. 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.'

**Research into M.E. 1988 - 1998 Too much PHILOSOPHY and too little BASIC SCIENCE!** by Dr Elizabeth Dowsett

'There are actually 30 well documented causes of 'chronic fatigue'. To say that M.E. 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'. 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.'

**Differences between M.E. & CFS** by Dr Elizabeth Dowsett

'M.E. 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 M.E. where they have been awarded for life. Many with M.E. commit suicide: in the UK, figures are said to run at one M.E. 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.

**The malign influence of Wessely School psychiatrists:** the extent of the influence of this group of psychiatrists is phenomenal: it extends not only to Government and its Departments of State but as noted above, to the medical insurance industry, as well as being rampant throughout the NHS and medical research establishments such as the MRC; it seems to encompass many medical journals and much of the media (including the BBC). Also as noted above, of concern is that this malign influence has now extended to the APPGME and to certain of the M.E. patients' charities, one of which (Action for M.E.) is actively colluding with the psychiatric studies being undertaken by Wessely School psychiatrists that are funded by the MRC. This collusion has given rise to substantial documented concern, primarily because if such Trials are to include those with authentic M.E., the Trials may be dangerous because of the evidence that patients may already be in significant cardiac failure, so participation in the Trials may therefore result in irreversible deterioration. No compensation would be payable for such deterioration, since participants are likely to be required to sign a consent form containing a no-liability clause.

A further and most disturbing effect of Wessely School influence has been on the M.E. charities themselves, whose charter requires them to act in the best interests of those with M.E. In the early days of their foundation, both charities (AfME and the MEA) produced excellent leaflets and information for both patients and physicians but gradually, possibly as a result of Wessely School influence, things changed and turned sour. In 1997, for example, members of the M.E. ForT campaign (Fighting for Truth) who produced a petition of over 14,000

signatures calling for the withdrawal of the 1996 Joint Royal Colleges' report --- a petition that was presented in the House of Lords by the Countess of Mar --- were threatened with legal action by the M.E. Association.

There is much unrest about AfME's close liaison with the Wessely School psychiatrists: that such liaison exists was spelled out by Michael Sharpe in his report entitled "Functional Symptoms and Syndromes: Recent Developments" in which he included "CFS" (for the reference, see above).

It is of interest that it is Professor Anthony Pinching who is AfME's Principal Medical Adviser. Currently, AfME takes the view that as a charity, it should not raise money to fund research into M.E. Quite certainly, AfME is not only supporting but is closely involved with the MRC psychiatric trials, as well as the new "Centres of excellence" that will deliver CBT and GET. It is of note that it is Professor Pinching who is Chairman of the Investment Steering Group that devised the process and criteria for the setting up of these Centres and who allocated the funds. Pinching is also lead adviser for the Department of Health on "CFS/ME".

The human rights of people suffering from M.E. are being conspicuously denied without any justification whatever. It is completely unacceptable that the unsubstantiated personal beliefs of a few immensely influential psychiatrists with indisputable vested interests should continue to indoctrinate UK medicine and the media regarding M.E. and that these psychiatrists should be permitted to impose inappropriate management regimes upon sick and defenceless patients on pain of having their benefits withdrawn if they do not comply, a situation that has continued unabated for far too long.'

#### **Hooper, M. & Marshall E.P. 2005b, Myalgic Encephalomyelitis: Why no accountability?**

'Undoubtedly the perverse use of chronic fatigue syndrome, to impose a psychiatric definition for M.E. 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 M.E., already carried out by several leading research groups, now requires significant funding.'

'The term Myalgic Encephalomyelitis has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. The current version ICD-10 lists M.E. under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination.'

'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 M.E. is a scandal and obscenity.'

#### **Myalgic Encephalomyelitis (M.E.): a review with emphasis on key findings in biomedical research by Professor Hooper 2006, printed in the BMJ**

'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 (M.E.), 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 M.E. 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 M.E.

There have been persistent and frequently covert attempts by these psychiatrists to subvert the international classification of this disorder, with destructive consequences for those affected. 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

Influenced by these psychiatrists, Government bodies such as the Medical Research Council have continued to propagate the same falsehoods with the result that patients are left without any hope of understanding or of health service provision or delivery. As a consequence, Government funding into the biomedical aspects of the disorder is non-existent

This 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 M.E.'

“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.”

**Hooper, M. 2003a, The MENTAL HEALTH MOVEMENT: PERSECUTION OF PATIENTS? A CONSIDERATION OF THE ROLE OF PROFESSOR SIMON WESSELY AND OTHER MEMBERS OF THE "WESSELY SCHOOL" IN THE PERCEPTION OF MYALGIC ENCEPHALOMYELITIS (M.E.) IN THE UK**

“We are aware that it is quite probable that some members of the Key Group (the "inner circle" of the CMO's Working Group on ME/CFS) intend to recommend that the CMO's Report should advise clinicians that only limited investigations are necessary for M.E. or CFS patients. Our understanding is that this specific advice comes from the Medical Director of the UK M.E. Association (Dr Charles Shepherd) and from those members of the Key Group who are known adherents of the "Wessely School". Such advice is merely repeating the message of the 1996 report on CFS of the UK Joint Royal Colleges, which states unequivocally that no investigations should be done to confirm the diagnosis.”

**Hooper, M. & Montague S 2001a, Concerns about the forthcoming UK Chief medical officer's report on Myalgic Encephalomyelitis (M.E.) and Chronic Fatigue Syndrome (CFS) notably the intention to advise clinicians that only limited investigations are necessary (The 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 M.E. 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.”

**Hooper, M. & Montague S 2001b, Concepts of accountability**

“Lawyers may wish to consider if a small group of exceptionally influential doctors should be allowed to determine public policy without there being some external moderation. They may wish to consider why disease definition has become socially constructed, resulting in political tensions between sufferers, medical science and the modern State, a consequence of which is the intentional construction of "mental illness" by some groups of medical professionals resulting in stigma caused by the on-going denial. If clinicians and lawyers are unaware of this background and accept the readily proffered psychiatric explanations as if objective and based on sound scientific research, they will be unable to support their patients / clients with M.E. and will risk failing in their professional duty in this difficult area.”

**Hooper, M. Marshall E.P. & Williams, M. 2001, What is M.E.? What is CFS? Information for Clinicians and Lawyers**

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

**The Terminology of M.E. & CFS by Professor Malcolm Hooper (undated)**

“There can be few people in the UK M.E. community who have not by now heard the results of the inquest into the tragic death from M.E. of 32 year-old Sophia Mirza, the beloved daughter of Criona Wilson from Brighton. Although severely sick with medically diagnosed M.E., Sophia was abused by the doctors charged with her care by being wrongly sectioned under the Mental Health Act. Increasingly in cases of M.E., the law which states that a person may be sectioned only if they represent a danger to themselves and / or to others is being swept aside by some influential but misinformed doctors involved with M.E.”

**Marshall, Eileen & Williams, Margaret. 2006b, Inquest implications**

“The M.E. 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 (M.E.) almost always to no avail, to the extent that the M.E. community realised that there were powerful vested interests at stake which were known to involve a group of psychiatrists known as the "Wessely School". ‘

**Marshall, Eileen & Williams, Margaret. 2005b, Proof positive? Evidence of the deliberate creation via social constructionism of "psychosocial" illness by cult indoctrination of State agencies, and the impact of this on social and welfare policy**

“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 M.E. (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.'

**Marshall, Eileen & Williams, Margaret. 2004b, Transparency in government**

"As a psychiatrist, I have to say that it is distressing how unconcernedly certain colleagues are abusing psychiatry, allowing interests other than those of the patients to take precedence".

**Williams, Margaret 2003, Quotations from "SOMATIC MEDICINE ABUSES PSYCHIATRY - AND NEGLECTS CAUSAL RESEARCH" by Per Dalen**

'Schaeffe: Children in America are being medicated to death—death by mind-altering drugs. [They] are coerced into mental health screening, they are forced into psychiatric treatment and they are prescribed dangerous psychotropic drugs. America's children are oftentimes denied contact with their parents, they are restrained without parental knowledge and they are given many different psychiatric medications. [End of quote.] This is not just a matter of classroom behaviour. We also see it, for example, in our own international M.E. communities.'

**COERCION, CORRUPTION AND CONSPIRACY: A LETHAL MIX.** By Gurli Bagnall, August 2005

'What is it was about the medical profession and psychiatry in particular, that attracts the sort of person [Professor Wessely] 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 fully clothed mother not jumped in to save him, he would have drowned.'

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

"You've got the fox in charge of the henhouse," DeAngelis said in an interview. "The pharmaceutical industry spent \$4.9 million in 2003 to lobby the FDA. That's like saying, I'm going to lobby the police department to keep cousin Guido from getting arrested for bootlegging." "In the interests of keeping ourselves safe from medical harm, and as citizens of democratic countries, it is up to each of us to resist tactics such as those mentioned above, and to do whatever we can individually towards bringing ethics back to medicine and in particular, the principle of "first do no harm".'

**COOKING THE BOOKS** by Gurli Bagnall, December 2004

'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?'

**PSYCHIATRY AND PERFDY** by Gurli Bagnall, July, 2004

"This will be revealed as one of the biggest medical scandals in history" declared a severe M.E. sufferer. "It is bad having severe M.E. 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."

**Comments By The 25% M.E. Group (Word format)** Comments from Greg Crowhurst December 2005

**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 M.E. 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" M.E. 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 M.E. patient survey, it was found that up to 50% were made worse by Graded Exercise Therapy. In the same survey, 93% found rest and pacing of their condition much more helpful in managing their illness.

**PRESS RELEASE & GENERAL STATEMENT By the 25% M.E. GROUP**

'The insurance companies known to be involved in [M.E. or '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 M.E. claim succeeding, because both the insurers and the re-insurers all use the Wessely School psychiatrists to inter-refer claimants with [M.E. or 'CFS']. Given that insurers can refuse to pay out on claims until the claimant with [M.E. or '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 but the clear evidence is that they do not, and are in fact harmful.'

**Notes on the involvement of Wessely et al with the Insurance Industry and how they deal with M.E. or CFS claims** by Stephen Ralph, June 2003

'As with Gulf War Syndrome, the evidence continues to be dismissed. That patients suffer indescribably and that many are completely abandoned by the State and are so without hope or support that they are driven to suicide seems to be of no consequence when weighed against costs implications to Government and to the industries which fund it. Despite all the published international evidence that M.E. is a serious, chronic and devastating neuroendocrine-immuno-vascular disorder, UK Government bodies have decreed that M.E. patients must not be fully investigated and that no research is to be undertaken into the disrupted biology; instead, all that is to be provided for such gravely sick people are more psychiatric "centres of excellence" which will deliver cognitive behavioural therapy and a psychiatric ascription (thereby excluding such patients from essential financial benefits necessary for basic survival).'

**Notes on recent research in M.E. and the Government's policy of denial** by Stephen Ralph, September 2003

'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 (I.M.E.) was skewed in favour of the company through the work undertaken by its claims adjusters and in-house doctors. Illnesses were characterised as 'self-reported' and so thrown into question. Only 'objective' test results were accepted. Some disabling conditions were labelled as 'psychological', which made them ineligible for insurance cover beyond 24 months. Doctors were pressured to use the 'subjective nature' of 'mental' and 'nervous' claims to the company's advantage. Specific illnesses were targeted in order to discredit the legitimacy of claims. The industry drew on the work of two of the Woodstock conference participants, Professor Simon Wessely of King's College and Professor Michael Sharpe of Edinburgh University, in an attempt to reclassify [M.E.] as a psychiatric disorder. Success would allow payouts to be restricted to the 24 month limit for psychological claims and save millions of dollars. By 1997 Provident had restructured its organisation to focus on disability income insurance as its main business. It acquired Paul Revere, and then in 1999 merged with Unum under the name UnumProvident.

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

**New Labour, the market state, and the end of welfare** by Jonathan Rutherford 2007: **Jonathan Rutherford looks at the connections between government and the insurance business in their joint project to reduce eligibility for sickness benefits.**

'The greatest threat right now comes not just from the psycho-corporate lobby; they are so easily exposed. It comes from the moderates, the lukewarmers, the compromisers right at the centre; who cannot see the damage they are doing by negotiating the truth away. Because the psycho/corporate lobby's truth is a relative one (to a political agenda), it can be infinitely flexible, so the goal posts can be constantly moved about by the corporate-psychiatric lobby and the real truth perverted, especially by the brilliant infiltration of patient movements. You simply cannot sit safely on the fence believing that you are being reasonable. There is no balance to be struck between psycho-corporatism and a true biomedical approach.'

**From M.E. advocates Greg and Linda Crowhurst in: M.E. Awareness: Check out the facts**

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

**Margaret Mead (1901-78)**

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

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

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

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



- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease with the ICD code G.93.3.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.
- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart. However, the hearts of M.E. patients only pump barely 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.