

## 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.

### Fatigue schmatigue

Copyright © Jodi Bassett March 2005. This version updated March 2009.  
Taken from [www.hfme.org](http://www.hfme.org)



It's a well-known fact that virtually everyone in the Myalgic Encephalomyelitis (M.E.) community absolutely loathes the name (and concept) of 'Chronic Fatigue Syndrome,' particularly for its use of the 'f' word – and for good reason. Yet when the same group of people describes the effects of the illness in their own words, it is not uncommon to hear *some percentage* of them go on and on about how 'fatigued' they are! It's bizarre when you think about it.

So what does the word fatigue really mean? 'Physical or mental weariness resulting from exertion. A feeling of excessive tiredness or lethargy, with a desire to rest, perhaps to sleep. Often it causes yawning' (Wikipedia, 2001[Online]) (American heritage dictionary, 2000).

Compare that definition to descriptions of M.E. given by some of the worlds leading experts (and/or authors and patients) in the field. The M.E. community has spoken out loud and clear against 'fatigue.'

M.E. expert Dr Elizabeth Dowsett (an award-winning microbiologist with 30 years' experience in M.E. research) comments that "‘Fatigue’ is the wrong word. Fatigue is a silly word." (Colby 1996, p. 167) Dowsett also comments that 'fatigue' is, 'A symptom common to hundreds of diseases and to normal life, but not a distinguishing feature of Myalgic Encephalomyelitis' (1999b, [Online])

Dowsett also writes that:

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" (n.d.a, [Online])

In Sick, Not Tired M.E. patient Ciara MacLavery writes:

I've lost count of the times medical staff have said to me: "I don't really know very much about ME. You get tired a lot, don't you?" No. I'm 35 and haven't been "tired" in the conventional sense of the word since I was a teenager. As anyone with severe ME will tell you, it has nothing to do with being tired and everything to do with being physically ill. On the many occasions I am unable to watch TV or hold a conversation, sit upright or walk more than a few steps, it is not because I am "tired". It is due to the fact that there is some catastrophic, metabolic imbalance within my cells that leaves me feeling poisoned and weak to the point of collapse. Muddying the waters further is the fact (sorely lamented by many sufferers) that ME is sometimes referred to as Chronic Fatigue Syndrome. Trust me, "fatigue" or "tiredness" don't even register on the scale of how life-shattering an illness this can be. Tiredness is to ME what forgetfulness is to Alzheimer's disease.

Professor Malcolm Hooper explains:

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 ME: 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

In the US in the late 1970s and 1980s there seemed to be a remarkable rise in incidence of ME, with manifestations of serious neuro-immune disease and profound incapacity, to the extent that the powerful insurance industry became alarmed. The insurance industry was concerned that, because there is no National Health Service in the US: "the field could change from an epidemiological investigation into a health insurance nightmare". The result was a determination to suppress the true symptomatology and to construct a new case "definition" for which insurers

could not reasonably be liable: the condition was henceforth to be called 'chronic fatigue syndrome' or CFS and emphasis was to be on chronic "fatigue" as the primary symptom

It is important to be familiar with the fact that "chronic fatigue" and chronic "fatigue syndromes" do not equate with ME. (2001, [Online]).

M.E. sufferer Terry Sweet writes, 'When I first found out what I had, I knew somebody was trying to hide something -- chronic fatigue my ass!'

M.E. sufferer Barbara L.R. writes, 'I feel sick, achy, weak, dizzy, jangly but not yummy old fatigue: like you get when you have walked to the beach, or dug a garden bed, or shopped till you dropped.' Another patient writes: 'Fatigue doesn't describe the main feature of M.E., it never has and it never will. If your worst symptom is fatigue you have a different illness.'

M.E. sufferer Barbara Gilliam writes, 'I too am hopeful that this illness will be treated with respect and recognized for the devastating handicap that it is... CHRONIC FATIGUE????? I don't think so!'

M.E. sufferer Tatyana writes,

I think it is the obsession with fatigue that allows doctors and the general public to minimise the debilitation and our inability to exercise or snap out of it. If you minimise the illness as merely fatigue then many people (including the doctors) will see it as something you can push through. After all we live in a society that doesn't respect listening to you body and resting when you need it - so a whole illness that encourages that behaviour has got to be just laziness. The protestant work ethic is alive and well and does not believe ME is anything but mental weakness.

M.E. advocate Cesar Quintero comments on the links between M.E. and polio, and comments:

We may never know [the extent of these links] if the government continues to cover up the existence of M.E. by calling it fatigue and confusing the public and doctors and fostering mythical subgroups. Confusing the understanding of this disease by opening the door for the inclusion of a multitude of unexplained fatigue conditions will choke off the support and investigation of Myalgic Encephalomyelitis.

Laura Hillenbrand, bestselling author of *Seabiscuit*, and M.E. patient, explained that, 'This illness is to fatigue what a nuclear bomb is to a match. It's an absurd mischaracterization.'

Dr Paul Cheney and Dr Dan Peterson describe the illness as 'A global disablement, nearly comparable to paralysis.' (Johnson 1996, p.34) Hillary Johnson explains that:

Peterson tried to convey the quality of the pervasive symptom, calling it 'absolutely striking – like nothing you have ever heard in taking histories before. This isn't tiredness. This is a carpenter who says, "I can't raise my arm to hammer," or a marathon runner who says, "I can't make it to the corner"' (Johnson 1996, p.34).

One psychologist well versed in standardised systems of evaluating the psychological import of words noted, the word 'chronic' is associated with chronic complainers, chronic whiners. And 'fatigue' is even worse (1996, p. 219).

[One sufferer writes:] 'There is nothing in your experience of medical school, residency, or practice with its gruelling hours and sleep deprivation that even approaches [what] you feel with this illness. Fatigue is the most pathetically inadequate term' (1996, p. 461).

Lynn Michell summarises what the M.E. patients she interviewed for her recent book, said about the illness:

It is as if someone has frayed the ends of every nerve in the body and left them raw and exposed. It brings an overwhelming need to close down sensory input and, for many, to retreat from everyday ordinary stressors - conversation, noise, light, movement, TV - since they are agonising to deal with. Everyone said that they were not fatigued. (2003, p.24)

Mitchell goes on to comment that:

[Legitimate descriptions of the illness are] a far cry from the hopelessly inadequate description of M.E. as 'chronic fatigue.' The distinction between fatigue and M.E. needs emphasising. If you are tired all the time, you do not have M.E. If you are feeling drained following a viral illness but are recovering over weeks or months, you do not have M.E. (2003, p.6).

This is not fatigue. This is a state of overstimulation which results in near or total collapse. One of the things that has been shown over and over again is that biologically [people with] M.E. have an inability to respond to stressors [or stimulus.] Although M.E. is sometimes described as a stress-related illness, what stress means in this context is 'the non-specific response of the body to any demand.' So, while healthy people cope with the demands which assault their senses, responding appropriately to what is relevant while ignoring what is not, people with ME have lost the ability to manage the sensory input of their environment (2003, p.28).

A central problem is the word 'fatigue' which doesn't come close to describing how sufferers can feel – comatose might be better. Like most people with ME I have acquaintances who say, 'Oh I feel tired at 4pm too, and would love a snooze.' But that's not it. People with ME are so finished that they have to lie down. There is no other option. Minds and bodies do not function. This is nothing like fatigue (2003, p.88).

At the turn of the millennium, the public still lacks a real grasp on what patients are dealing with. Because of illusions that M.E. is simply a disease of tired people the public has large been deprived of accurate information (2003, p.xxii).

The Committee for Justice and Recognition of Myalgic Encephalomyelitis explain that:

All definitions which wear the 'f' word (ie. fatigue) in their name are not M.E. nor neurological. They are definitions of fatigue conditions. And when these definitions were written it was not neurological M.E. which they were attempting to define.

When Holmes *et al.* 1988 was written - the condition which they were trying to define was Chronic Epstein Barr Virus. The principal symptom was 'fatigue'. It is interesting to note that those who were familiar with M.E. on the committee refused to sign off on this definition - as they pointed out that it was not a definition of M.E.

Dr David Bell shuns the use of the word fatigue, describing it as:

A very inappropriate term for what patients experience. It's not really fatigue at all, which is defined as a normal recovery state from exertion and that is precisely what does NOT happen in this illness. They may say they're fatigued, but what's really restricting their activity may be pain, tremulousness or weakness - a sense that they are on the verge of collapse. That is not fatigue as we commonly think of it. (1995)

Patient advocate Jill McLaughlin writes, 'Advertising fatigue or studying it or analyzing it by fatigue scales or holding fatigue conferences or setting up fatigue clinics is not going to help those with underlying neurological illnesses' and adds that, 'No one fears fatigue.' She continues:

The prominent association of fatigue with psychiatric disorders has greatly contributed to the erroneous psychological attributions of the illness, much to the detriment of patients. This has led to the trivialization of the illness as little more than a manageable, unexplained fatigue state and the misperception that it may be treatable by little more than counselling, OTC medications, antidepressants and lifestyle changes. It is the focus on fatigue has created much confusion and misunderstanding during the past decade.

Authors Verillo and Gellman explain:

The term "fatigue" does not do justice to what people actually experience. People with M.E. often find themselves at a loss for words when it comes to describing how they feel. Patients come to doctors saying they feel "crushed," "totally wiped out," "comatose," or "paralysed" or use descriptive phrases such as "I feel like I've been hit by a truck," "I can't get out of bed," or "I can't lift my toothbrush." The truth is that M.E. is unique. In its severe form it can be all-encompassing, which can be devastating. It can rob a person of livelihood, family, career, hope, will, and feeling. The terms currently available do not convey the profound loss produced by M.E. More than an understatement, however, the word "fatigue" is misleading because its widespread use has led to a dismissive attitude on the part of the medical establishment.

There is nothing normal or natural about the [symptoms] experienced by people with M.E. Unlike the state of tiredness a person might feel after a busy day, the [symptoms] produced by M.E. [are] not relieved by a good night's sleep, a workout, a protein snack, a change in lifestyle, a vacation, or any of the other measures that normally help the healthy person "recharge." The reason none of these measures work is self-evident. M.E. [symptomatology is] not the natural product of exertion. It is a reflection of the profound metabolic, neurologic, and immunologic dysfunction wrought by illness (1996, p. 77).

In the book 'Stricken' Peggy Munson explained that:

The symptoms of M.E. resemble and improbably hypoxic state, so far from normal tiredness, so much more of an all-body impairment, than the word fatigue could ever convey. As Chris Norris wrote in New York Magazine, 'If this is fatigue, its relationship to workaday weariness is as Satre's nausea to an upset tummy. I have been tired before. This is not tired' (2000 p. 114)

M.E. expert Dr Byron Hyde explains that, 'The whole concept of fatigue has warped our understanding of this illness' and that;

The one essential characteristic of M.E. is acquired CNS dysfunction, [not] chronic fatigue. Fatigue is immeasurable and largely indefinable. Fatigue is a normal phenomenon as well as being associated with almost all chronic disease states. Fatigue, which is simply one of the common features of healthy life and disease, neither defines M.E. nor clarifies the illness. The term 'fatigue' **does** cause disparagement to those who study this serious debilitating illness and those who suffer from it (1992, p.18)

The problem with fatigue is that it is neither specific, definable nor scientifically measurable. Fatigue is both a normal and a pathological feature of every day life. Every normal person gets fatigued. Fatigue is a common feature of much major psychiatric disease and major medical disease. Fatigue is not an object, it is simply a modifier in search of a noun. Also, taking fatigue as the flagship symptom of a disease not only bestows the disease with a certain Rip Van Winkle humour, but it removes the urgency of the fact that the majority of M.E. symptoms are in effect CNS symptoms.

M.E. represents a major attack on the CNS by the chronic effects of a viral infection. ME is a systemic disease with many systemic features, but it is characterised primarily by CNS dysfunction [and not by] fatigue. (1992, pp.11-12)

Fatigue is a totally indefinable concept. Fatigue is impossible to measure or quantify. Fatigue is so non-specific that it can be a common element in any acute or chronic disease and many psychiatric diseases. Worse, it redirects the medical and public attention away from the obvious Central Nervous System changes in these patients. Much worse, it makes fun of a serious illness. It has turned out to be a damning indictment to all M.E. patients (2006, [Online])

- These are just a few of the leading M.E. experts who have spoken out against 'fatigue' being the defining feature of M.E., [click here](#) for more, or see: *Smoke and Mirrors*. (Note that Dr Bell/Dr Peterson can in no way currently be described as M.E. experts and that the issue of whether or not [Dr Cheney](#) is a M.E. expert is a grey area unfortunately as he describes the abnormalities unique to M.E. and clearly deals primarily with M.E. patients yet he uses terms such as 'CFIDS' and includes some poor quality 'CFS' information with his research findings.)

**It's not only that Myalgic Encephalomyelitis is 'more than just fatigue' as you hear so often, the real issue that we all seem to have missed entirely – is that it's not fatigue at all.**

I had the flu recently and with it I experienced quite a bit of genuine fatigue. I felt extremely relaxed and drowsy and had lots of little naps throughout the day, I just couldn't seem to stay awake. It really brought home to me the reason why there is such utter public apathy about M.E.: fatigue really isn't that unpleasant! It is also not in any way, shape or form the main feature of M.E. If only it were.

Myalgic encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. Central nervous system (CNS) dysfunction, and in particular, inconsistent CNS function is undoubtedly both the chief cause of disability in Myalgic Encephalomyelitis and the most critical in the definition of the entire disease process. Myalgic Encephalomyelitis also causes a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits.

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

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically.

What characterises M.E. every bit as much as the individual symptoms however is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain (the CNS) this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) in M.E. include:

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

- B. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.
  - C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
  - D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient's pre-illness tolerances and abilities.
  - E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
  - F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.
  - G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.
  - H. The activity limits of M.E. are not short term: a gradual (or sudden) increase in activity levels beyond a patient's individual limits can only cause relapse, disease progression or death in patients with M.E.
  - I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion; there is also a base level of illness which can be quite severe even at rest.
  - J. Repeated overexertion can harm the patient's chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
  - K. Not every M.E. sufferer has 'safe' activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected (Bassett 2009, [Online]).
- For the full-length version of this text and for a full list of references for this text see: [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#).

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

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

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

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

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

- See *The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List* for more information (and for a full list of references).

These descriptions are undeniably nowhere near as simple as just using the ‘f’ word (or talking about tiredness or lack of ‘energy’ or ‘stamina’) but they do have cold hard accuracy going for them! A real description of M.E. does not resemble anything that could be called ‘fatigue’ or have any similarity with being ‘tired all the time.’ Comparing ‘fatigue’ with the symptomatology of Myalgic Encephalomyelitis is like comparing a flea to a nuclear missile or... a hedgehog to a three-storey house with an indoor pool – there is no comparison.

M.E. is a serious acquired illness that can severely disable or even kill you; it’s absolutely **nonsensical** that M.E., and the sensation of tiredness felt after exertion by healthy people, could both be described using the exact same word.

**So why do we use the ‘f’ word so often if it’s so inaccurate?** Perhaps we assume that if we have an illness that is sometimes (misleadingly and *incorrectly*) called ‘CFS’ that our main problem *must* then be fatigue; a completely logical assumption to make, provided that the name was chosen in good faith (and for sound medical reasons) in the first place and provided that M.E. and ‘CFS’ were synonymous terms. Except that it wasn’t, and they aren’t. Hillary Johnson, author of a book which documented the mid-eighties M.E. outbreak in the US (Osler’s Web), explains that the name 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”. (1996, p.219)

The word fatigue and the ‘CFS’ definitions were used to make sufferers of the illness appear tired instead of ill, unable to cope psychologically with the normal pressures of modern life certainly, but not really any sicker than anyone else. Indeed the terms ‘fatigue’ and ‘chronic fatigue’ were not associated with this illness at all until ‘CFS’ was created in 1988 (Hyde [Online]). The ultimate goal of such word choices was undoubtedly to save the Government (and other organisations such as insurance companies), billions of dollars; money saved from all the services that these groups would have been obliged to provide (and pay for) if this were to be seen as a ‘real’ and organic illness. (Hooper et al. 2001 [Online]) Because of the political motivations behind the naming of this illness, the common and seemingly logical assumption that our symptoms – no matter how far they deviate from or even completely contradict all known definitions of the word – must still be ‘fatigue’ because of the concept of ‘CFS’ is in fact completely illogical. **The ‘f’ word was selected entirely for what it could achieve politically: it was never intended to be a genuine medical description of the symptomatology of this illness.**

Maybe our readiness to use the ‘f’ word is also due to the fact that some of us (the M.E. community) have given it our own special meaning? Because *of course* we all know that it’s not just tiredness that we’re experiencing, use of the ‘f’ word is always quickly followed by an explanation of what we actually mean by the word. We use a word that means ‘A’, and then say, ‘but by A, what I mean is B.’ So of course people are always going to think that although we said B afterward, that what we must really mean is A, as after all, that was the terminology we used.

Perhaps the biggest issue surrounding our use of the ‘f’ word though, is that there is no perfect alternative SINGLE word just waiting for us. Myalgic Encephalomyelitis is an extremely severe and complex multi-system illness and there just aren’t any individual words that come even close to describing its full horrors – but we can still do better than the pathetically inadequate and politically damaging ‘f’ word. Surely its mere ease of use can not make up for its utter inaccuracy and myriad other disadvantages? Is it really better to use a very inaccurate single word than to come up with a few sentences which at least make some attempt to do the illness justice?

**But surely one little word hasn’t caused all of the credibility problems that M.E. has?** No, of course it didn’t, the way the illness was re-branded as the fatiguing illness ‘CFS’ was just a brilliant starting point. It meant that the illness was disassociated from its previously established name (Myalgic Encephalomyelitis) and from all its previous research and case studies dating back to 1934 (Quintero 2002 [Online]). This then left the path clear for the Government (and the other financial stakeholders) to basically re-write history to suit themselves, to create new definitions of the illness which excluded all of the cardinal symptoms of M.E. and instead focused almost entirely on ‘fatigue.’ It was also made a condition of the diagnosis that there be no observable physical signs of illness – this despite the fact that such signs are *always* present in M.E. patients. (Hooper et al. 2001 [Online])

With these new ‘definitions’ of ‘CFS’ illness in place, the creation of a substantial body of research to back up this bogus disease category of ‘CFS’ was only too simple. This pseudoscientific research – conducted primarily by the US Government as it was – was seen by a trusting public as being completely and unquestionably credible, this despite the absolutely enormous holes and inconsistencies in it both scientifically (and even just plain logically) when you looked at it close up. The problem, as we all know, is that almost nobody ever did.

The way the illness was re-named and redefined (supposedly) as ‘CFS’ and branded as a psychologically based ‘fatiguing illness’ was clearly just the first stage (for the stakeholders involved), in concealing the truth about M.E. from the public; the foundation as it were.

**But who says that WE can’t use words as weapons too?** It’s a commonly held belief (in the M.E. community) that as soon as we have enough good solid evidence, that the medical recognition so long overdue will somehow be forced to instantly materialise. That all those doctors who deny the reality of M.E. will have no choice in the face of such rock-solid research but to concede that they were wrong. The reality is that there is already an *abundance* of credible research that has unequivocally demonstrated an organic pathology for M.E.; and very little has actually changed. But is this really so surprising? As long as the main feature of M.E. is seen to be fatigue, legitimate research into M.E. and the sham science that is sponsored by financial stakeholders, will be seen as interchangeable. Then it is all too simple for all of the genuine, reputable and complex M.E. research to be ignored in favour of the easy (and inexpensive) answers that are associated with studying the symptom of fatigue. Good science alone will never be enough; we also need to disassociate the ‘f’ word from this illness so that the legitimate Myalgic Encephalomyelitis research can finally stop being so easily buried under the suffocating weight of the inaccurate typecasts of mere ‘fatigue.’

- For more information on this point see: [Are we just 'marking time?'](#)

Many M.E. patients and advocates are also (understandably) anxious to get the name of the illness changed away from ever being referred to as ‘CFS’ before anything else. But this must be done properly, as merely renaming ‘CFS’ as M.E. (as some CFS advocates are arguing for) would be an absolute DISASTER. It would make our problems with advocacy far more serious and dire (and further disadvantage all those misdiagnosed with CFS also). None of the definitions of CFS define any distinct illness including M.E., thus renaming the wastebasket diagnosis ‘CFS’ as M.E. is illogical and ill advised. The only solution is that the bogus disease category of CFS must be abandoned, and that people with authentic Myalgic Encephalomyelitis must again be diagnosed with M.E. The name M.E. must be renewed; this is not the same thing as renaming CFS as M.E. at all.

- For more information on this point see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename ‘CFS’ as ‘ME/CFS’ and Problems with the use of 'ME/CFS' by M.E. advocates, plus The misdiagnosis of CFS, Why the disease category of ‘CFS’ must be abandoned and Smoke and Mirrors](#)

BUT even if the name M.E. were renewed, would it really make any difference if those with the illness continue to use the ‘f’ word to describe the illness, and continue to be accepting of it’s use by others? How can a name renewal possibly achieve anything if this also remains a ‘fatiguing’ illness, with everything that that entails?

But what if just by refusing to use or accept one word we could finally start to change things for ourselves? We may be stuck with the jargon of the name officially but we can at least stop ourselves (and those around us) from describing its absolutely horrific effects in such an utterly ridiculous and harmful way.

**It’s as simple as talking about how ill you are, instead of how ‘fatigued’ (or ‘tired’, or low on ‘energy’ or ‘exhausted’) you are.** If we only stopped the use of the ‘f’ word - and other words just like it - within the M.E. community and amongst our friends and family, that would be a fantastic start, and who knows where it might lead? At the very least, by disassociating ourselves with fatigue, perhaps it will stop every second person we meet from saying ‘Oh yeah, I think I might have that, I get really tired sometimes too.’

The possibilities are endless and we risk nothing by trying. It’s true that before fully escaping the stigma of fatigue attached to M.E. that we desperately need more research funding and education campaigns, as well as decent standardised criteria to diagnose and define the illness, as well as the name and definition of authentic Myalgic Encephalomyelitis to be renewed, as per the World Health Organisation’s International Classification of Diseases since 1969. But no matter how you look at it, eradicating the ‘f’ word *has to be* an integral part of obtaining all of these other objectives too.

Every journey must begin with one step, and this first step is so simple and for once, totally within our control AND our very limited abilities! So just stop using and accepting the ‘f’ word, starting from today. **Let’s see where this first step might take us. ...**

**For more information:**

- For more information about the medical and political facts of M.E. see: [What is Myalgic Encephalomyelitis? Extra extended version](#), [Who benefits from 'CFS' and 'ME/CFS'?](#), [The misdiagnosis of CFS](#), [Why the bogus disease category of 'CFS' must be abandoned](#), [Smoke and mirrors, M.E. The Medical Facts - Extended](#), [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#), [Testing for Myalgic Encephalomyelitis and Putting research and articles into context](#).
- To read a list of all the articles on this site suitable for different groups such as M.E. patients, carers, friends and family, the 'CFS' misdiagnosed, doctors or severe M.E. patients and so on, see the [Information Guides](#) page.
- See [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#) for more information about the symptomatology of M.E.
- See (the imaginatively titled) [Energy Schmenergy](#) for more information about the use of the terms 'energy' and 'exhaustion' in M.E. See also if not 'fatigue' then.. what? for further discussion and ideas on alternate terminology. These texts are reprinted below.

**Additional notes on this text:**

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

The terms 'fatigue' and 'chronic fatigue' were not associated with defining this illness at all until the new name (and definition) of 'Chronic Fatigue Syndrome' was created in 1988 in the USA (Hyde 2006, [online]). But M.E. and CFS are *not* synonymous terms.

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

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

- For more information see [Myalgic Encephalomyelitis is not fatigue, or 'CFS'](#). Many of the worlds leading M.E. experts have spoken out strongly against 'fatigue' being claimed to be the defining/essential symptom of M.E. see [M.E. is not defined by 'fatigue'](#) to read some of their comments. For more information on the symptoms of M.E., including the unique reaction people with M.E. have to activity (etc.), see: [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#)

**Further notes:**

- *Also note that:* repeated or severe overexertion can also cause disease progression, permanent damage (eg. to the heart), or death in M.E. patients. Again, to suggest that these very serious and long-term effects – and fatalities – could be accurately summarised as being a problem of mere 'fatigue' is clearly absurd



- *An additional note on 'fatigue'*: The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, muscular, gastrointestinal and other symptoms and characteristics (and so on) – the presence or absence of mere 'fatigue' is irrelevant. In addition to these other (far more serious) symptoms, some M.E. sufferers may also suffer with mild, moderate or severe fatigue some of the time, while others will not. Thus the symptom of fatigue is not an essential symptom of M.E. and does not define M.E. (Although the symptom of fatigue *is* essential to qualify for a misdiagnosis of 'CFS'). For more information see: [M.E. is not defined by 'fatigue'](#) and [The misdiagnosis of CFS and M.E. is not fatigue or 'CFS'](#)
- *A note on terminology*: It is important to be aware that Myalgic Encephalomyelitis and 'CFS' are not synonymous terms and should not be used interchangeably, and that 'fatigue' is not a defining feature of M.E. nor even an essential symptom of M.E. CFS was created in the 1980s in the US in 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 fact that a person qualifies for a diagnosis of 'CFS' (a) does not mean that the patient has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' Every diagnosis of CFS – based on any of the CFS definitions – can only ever be a *misdiagnosis*.

The bogus disease category of 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various psychiatric fatigue states and various unrelated fatigue syndromes for the benefit of insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government. *The distinction must be made between terminology and definitions.* In short:

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

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

For more information on why the bogus disease category of 'CFS' must be abandoned, (along with the use of other vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'CFIDS' and 'Myalgic Encephalopathy' and others, including 'ICD-CFS'), and why renaming, refining or sub-grouping 'CFS' cannot work see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [What is Myalgic Encephalomyelitis? Extra extended version](#), [The misdiagnosis of CFS](#), [Why the disease category of 'CFS' must be abandoned and Smoke and Mirrors](#).

## References:

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

studies and articles on M.E., and books (or chapters in books) on M.E. Again, more experienced, more knowledgeable and more credible M.E. experts than these simply do not exist.

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

- Bassett, Jodi 2009. *The ultra-comprehensive M.E. symptom list* [Online], Available: <http://www.hfme.org/themesymptomlist.htm>
- Bell, David S MD 1995, *The Doctor's Guide to Chronic Fatigue Syndrome*, Perseus Books, Massachusetts
- Colby, Jane 1996, *ME: The New Plague*, Ipswitch Book Company Ltd, Ipswitch
- Dowsett, Elizabeth MBChB. 1999b, *Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC CIENCE!*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. n.d. a, *Differences between ME and CFS*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Hooper, M. Marshall E.P. & Williams, M. 2001, *What is ME? What is CFS? Information for Clinicians and Lawyers*, [Online], Available: <http://www.hfme.org/whooper.htm>
- Hyde, Byron MD. The Nightingale Foundation, [Online], Available: <http://www.nightingale.ca/index.shtml>
- Hyde, Byron M.D. 1992, *Preface* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa
- Johnson, Hillary 1996, *Osler's Web*, Crown Publishers, New York
- Michell, Lynn 2003, *Shattered: Life with ME*, Thorsons Publishers, London
- The American heritage dictionary, Fourth edition, 2000, Houghton Mifflin Company.
- The ME Society of America website 2005, [Online], Available: <http://www.cfids-cab.org/MESA/framework.html>
- Quintero, Sezar 2002, *Sophisticated Investigation, or How to Disguise a Disease*, [Online], Available: <http://www.geocities.com/sezar99q/>
- *Wikipedia: the free encyclopaedia* 2001, Wikimedia Foundation, Inc. [Online], Available: <http://en.wikipedia.org>

**One final note:** If you are reading this and thinking 'but genuine fatigue really is one of my worst symptoms, and what is all that about serious neurological and cardiac problems...that doesn't sound much like me at all; no way is what I have primarily neurological, and it didn't start suddenly/acutely either, and I really undoubtedly do have a lot of genuine fatigue and tiredness!' etc. ....then I would **highly** recommend that you immediately and seriously look into the issue of misdiagnosis, and read the paper: [The misdiagnosis of CFS](#). Getting a correct diagnosis is just so important. It's half the battle won!

It seems very likely that much of the focus still put on 'fatigue' and 'exhaustion' in M.E. comes from those doctors treating primarily or totally non-M.E. patient groups and who do not understand the vast difference between M.E. and 'CFS' and patients who identify as having M.E. or who have accepted a diagnosis of M.E. in good faith yet do not in fact have M.E.

So often stories come out about longtime M.E. advocates who have turned out not to have M.E. at all but who were sure this was their correct diagnosis because of course 'they suffered enormously from the profound fatigue and exhaustion that characterises M.E.' This is yet another reason that it is so important that a) M.E. patients make it very clear that severe exhaustion is NOT what defines or characterizes M.E. but in fact it is something very different and unique involving cardiac insufficiency etc., and b) That everyone who identifies as having M.E. (no matter how long they have identified as M.E.) make sure that this truly is their correct diagnosis and that they (or their doctors) haven't instead been looking at definitions labeled as M.E. but which are in fact only meaningless 'CFS' or 'ME/CFS' definitions, and so on. If there is any doubt at all, please look into the issue of misdiagnosis.

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

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

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

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

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

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

**Permission is given for this document to be freely redistributed** by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author's attribution) is reproduced in full and without alteration. Please redistribute this text widely.

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

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

*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.

Copyright © Jodi Bassett, January 2009. This version updated May 2009.

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, Algie = 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.

*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.*

## Energy schmenergy

Copyright © Jodi Bassett May 2006. This version updated March 2009.  
Taken from [www.hfme.org](http://www.hfme.org)



I wrote Fatigue Schmatigue some time ago now, and I've had a really positive response to it which is great. I have noticed however, that what some people are replacing 'fatigue' with the word 'energy.' People with Myalgic Encephalomyelitis (M.E.) who wouldn't dream of using the 'f' word will instead say things like 'I just don't have enough energy to do that' or 'some people with M.E. use so much of their precious energy on activism' etc. **But using the term 'energy' has all the exact same problems as the word fatigue!** The term makes us sound tired or depressed instead of ill and also gives those around us a very misleading idea about what it feels like to actually have M.E. and about what M.E. is. It also damages us politically. This is why I have put together this short informal follow-up piece to discuss the concept of 'energy' in a bit more detail.

**My own experience...** For me, my 'energy' levels are just utterly irrelevant to how much activism work or anything else I do. My orthostatic and other heart problems, neurological and cognitive deficits, paralytic muscle weakness (and also a wide and varying amount of other symptoms) always kick in and stop me doing things way before my 'energy' ever runs out and I feel 'fatigued.' The reason I spend only a half hour or hour on the computer at a time is because; my cognitive problems have worsened to the extent I can no longer read or write, I feel immense pressure on my chest and my heart is beating all wrong, my eyes burn, my back and neck are in spasm and my arm muscles are becoming unresponsive and painful, I feel like I've been poisoned and like there is battery acid running in my veins instead of blood and/or it feels like I am having some sort of seizure. My level of disability is just not about my energy levels at all; it is about specific cardiac, neurological and other symptoms. It is about being very ill, not very 'tired.'

Amongst M.E. sufferers and the vast amount we all have in common, there is also of course some variability in which features and symptoms of the illness are dominant in each person. For one person it might be the cognitive problems, in another the paralytic muscle weakness and metabolic problems, in another person it might be the severe pain. **But even accounting for this difference in severity and the variability in symptom expression, I still just plain disagree that talking about 'low energy' cuts it when you are describing the devastating and utterly disabling symptom complex of M.E.** It just minimises the intense suffering caused by M.E., and makes it sound so much more mild and innocuous than it is... It makes it sound as if the only payback we have to worry about from overdoing it is tiredness, when the reality is so very different and so much more severe.

**What having no energy (or being exhausted) really feels like...** Before we were all unlucky enough to get M.E. we had felt low on energy before and are all familiar with the sensation. Do you remember how it really felt to have no energy left at the end of a long and productive – or really fun – day? Does how you feel now, with M.E., really feel the same as that? Did being worn out and having no energy when you were healthy, hurt in the same way as having a severe M.E. relapse does? Did it make you feel so severely ill that you felt like you might actually die from it like sometimes happens when you have M.E.? Are the sensations of having 'no energy' and of having M.E. in any way similar? **Of course they aren't!**

**What having M.E. feels like...** In my Symptom List I describe M.E. symptomatology as being a combination of: Profound cognitive dysfunctions (and various other neurological disturbances), muscle weakness (or paralysis), burning eye pain or burning skin, subnormal temperature or low-grade fever, sore throat or painful lymph nodes (and/or other signs of inappropriate immune system activation), faintness, weakness or vertigo, loss of co-ordination, dyspnoea, an explosion of sensory phenomena (low level seizure activity), cardiac and/or blood pressure disturbances, facial pallor and/or a slack facial expression, widespread severe pain, nausea or feeling as if 'poisoned,' feeling cold and shivering one minute and hot and sweating the next, anxiety or even terror (as an organic part of the attack itself rather than as a reaction to it) and hypoglycaemia. There may also be an accompanying exacerbation of many other symptoms. These symptoms often combine to create an indescribable and overwhelming experience of terrible illness that is unique to M.E. and can be profoundly incapacitating. At its most severe, the patient feels as if they are about to die.

Each of the symptoms caused or exacerbated by overexertion can be clearly articulated without difficulty. It makes no scientific or logical sense to subsume these very specific symptoms, and very specific and varied combinations of symptoms, under a vague and inaccurate label of mere 'fatigue.' To say that all of these very

different and very specific – and in some cases very serious – symptoms can be accurately summarised as being a problem of mere ‘fatigue,’ ‘malaise’ or ‘exhaustion’ or ‘having no energy’ is absurd.

Tiredness/fatigue/having no energy/exhaustion are all normal physiological responses and normal recovery states from exertion which occur in healthy people and are a normal part of life for everyone. M.E. in contrast is a distinct disease state that can severely disable or even kill you. The two problems are quite clearly apples and oranges, chalk and cheese – entirely different in every way.

**But if we need rest doesn't that mean we must be tired or have no energy?...** No, it doesn't. Just because there is a need for rest this does not mean that the problem is energy related; the two are not always linked. Rest is also necessary when there is an injury to the body (such as a broken leg) and rest is necessary for healing (and to prevent further damage) or when bodily processes are dysfunctional through illness and the body cannot cope with a normal workload. M.E. expert Dr Byron Hyde explained recently that when M.E. patients muscles and brains (and organs) stop working so suddenly and leave us incapacitated and forced to rest and/or with greatly reduced quality of function part of what is happening is that the cells are actually shutting down to prevent cell death. Considering this, do you think that what healthy people feel when they say they ‘have no energy’ is even *remotely* the same as what people with M.E. feel when they use the same phrase? **Of course not!**

**Does having clinical depression feel the same as having M.E.?...** Along with the symptom of fatigue, a feeling of having ‘absolutely no energy’ is listed as being one of the most common and most disabling symptoms of clinical depression. Considering the myriad of serious physical problems that we know are causing the symptoms and illness in people with M.E. (ALL of which are NOT present in people with depression) do you think that what depressed people feel when they say they ‘have no energy’ is even *remotely* the same as what people with M.E. feel when they use the same phrase? **Of course not!**

**When people with M.E. say they have ‘low energy’...** I think this is because there is just no word invested yet that truly describes everything that makes up the symptomatology of M.E. But the thing is, there NEVER will be! (Overexertion causing a worsening of all symptoms and of the severity of the illness generally due to decreased circulating blood volume etc..) But what we do know is that ‘tired’ is the wrong word. ‘Fatigue’ just means very tired and is also the wrong word. The term ‘energy’ is very similar to both these words and is not accurate either and ‘exhaustion’ just means really, really tired. Many different novel and articles use each of these term INTERCHANGEABLY! To draw a big distinction between ‘fatigue’ and exhaustion and so on just makes no sense. Whatever word you say, the only message that will get out is that you aren't ill but just a bit tired; tired in just the same way every healthy person gets sometimes. No big deal.

All of these terms describe a normal state of recovery after exertion in healthy people. People with M.E. are not healthy, their symptoms are not a normal state of recovery the symptoms of M.E. also occur even after (and during) extensive complete rest. This might seem trivial to some of you, but I think that those of us who are well enough to educate ourselves about the correct and non-propagandising terminology should do so and that this is an important part of M.E. advocacy.

**The bottom line is....** There are a group of extremely powerful vested interest psychiatrists (and others) who for financial and political gain pretend to the world that M.E. could be a psychological or behavioural illness and that in reality people with M.E. are physically healthy. These people have caused so much suffering, abuse and neglect for so many people with M.E. and have been responsible for thousands of deaths from M.E. Why would we want to make their job so much easier for them and play right into their hands by describing our utterly devastating symptoms in the exact same terms as those used by healthy people and depressed people?

So there isn't one word which describes M.E. symptoms. Big deal. There never will be! Is it so hard to just tell people you are ILL or have cardiac insufficiency, or have a disease similar to MS etc. instead of saying you are just ‘tired’ or ‘have no energy’ or are merely ‘exhausted.’ Is it that hard to then list a few individual symptoms if they ask for more information? After a little bit of practice, the answer has to be ‘hell no!’ and ‘why on earth wouldn't you?’

#### **For more information/additional notes**

- See Fatigue Schmatigue and Myalgic Encephalomyelitis is not fatigue, or 'CFS' for more information (as all the exact same arguments apply to the terms ‘energy’ and ‘exhaustion’).
- See: What it feels like to have M.E. and The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List and What is M.E.? for more information on the legitimate symptoms of M.E. and the politics surrounding M.E.
- See If not fatigue then... for more information about alternate terminology and correct descriptions of M.E.

- Feelings of fatigue or having low energy can sometimes (but not always) be a minor part of the symptomatology for some people with M.E., some of the time. But if you are reading this and thinking 'but genuine fatigue/low energy really is one of my worst symptoms, and what is all that about serious neurological and cardiac problems...that doesn't sound much like me at all etc. then I would **highly** recommend that you immediately and seriously look into the issue of misdiagnosis, and read the paper: [The misdiagnosis of CFS](#). A correct diagnosis really is half the battle won.

It seems very likely that much of the focus still put on 'fatigue' and 'exhaustion' etc. in M.E. comes from those doctors treating primarily or totally non-M.E. patient groups and who do not understand the vast difference between M.E. and 'CFS,' and patients who identify as having M.E. or who have accepted a diagnosis of M.E. in good faith yet do not in fact have M.E.

So often stories come out about longtime M.E. advocates who have turned out not to have M.E. at all but who were sure this was their correct diagnosis because of course 'they suffered enormously from the profound fatigue and exhaustion that characterises M.E.' This is yet another reason that it is so important that a) M.E. patients make it very clear that severe exhaustion is NOT what defines or characterizes M.E. but in fact it is something very different and unique involving cardiac insufficiency etc., and b) That everyone who identifies as having M.E. (no matter how long they have identified as M.E.) make sure that this truly is their correct diagnosis and that they (or their doctors) haven't instead been looking at definitions labeled as M.E. but which are in fact only meaningless 'CFS' or 'ME/CFS' definitions, and so on. If there is any doubt at all, please look into the issue of misdiagnosis.

**Permission is given for this document to be freely redistributed** by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author's attribution) is reproduced in full and without alteration. Please redistribute this text widely.



*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.*

## If not 'fatigue' then...what?

Copyright © Jodi Bassett May 2006. This version updated March 2009.  
Taken from [www.hfme.org](http://www.hfme.org)



Okay so you've read Fatigue Schmatigue (and Myalgic Encephalomyelitis is not fatigue, or 'CFS') and are determined not to use the words 'fatigue,' 'no energy' or 'exhaustion' to describe M.E. ever again. So what do you replace them with? Well that's up to you, but basically ANY real description! Anything that isn't about fatigue, or energy or exhaustion and IS instead about being seriously ill and the actual symptoms and pathology of M.E.

I think one of the easiest ways to go about it is to say that you are 'ill' instead of fatigued, it's a much more accurate word as truly it is illness that prevents us from doing as much as we would like, not a lack of mere energy or fatigue. It also leaves the way open for the person to then ask you "ill in what way?" and then you can list your most severe symptoms if you think they really want to hear them...

- Or else you could explain that you have a neurological illness which also affects almost all the different systems in your body. That you have a neurological illness which also causes cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal problems. (if you can remember all that!)
- Or you could tell people simply that you have M.E., an illness that is a cross between polio, multiple sclerosis and Lupus. Or just say that it's very similar to MS and show them the paper: M.E. vs MS: Similarities and differences – this is one of the very best options.
- Or that you have an illness which means that your body cannot complete all the bodily processes necessary for you to be able to do as many things as you'd like.
- Or that when you do any form of exercise beyond your limits, your body has a severe response and there is a worsening of all your symptoms. Tell people your illness is all about cardiac insufficiency. Tell them it is very serious and can sometimes be FATAL. Tell them you must limit activities in order to stay alive.
- Or you could explain that your cells aren't functioning properly which means all your muscles and organs also aren't functioning properly and that this means you are severely limited in how physically active you can be and even how much you can do intellectual tasks. Add that doing too much makes you very ill and that sometimes this is immediate but sometimes there is a delay of several days until the relapse hits.
- Or you could just talk about whichever symptom or group of symptoms is causing you the most trouble that day.
- Or you could explain that "the correct name for my illness is Myalgic Encephalomyelitis. It was named M.E. in 1956. It is not at all the same thing as 'CFS' and my symptoms are actually..."
- Or you could even use terms like 'I feel half dead' or 'I am too dead to do that today' etc. instead of talking about mere fatigue or energy.

Or you could explain that:

Myalgic encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. Central nervous system (CNS) dysfunction, and in particular, inconsistent CNS function is undoubtedly both the chief cause of disability in Myalgic Encephalomyelitis and the most critical in the definition of the entire disease process. Myalgic Encephalomyelitis also causes a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits.

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly



contribute to both of these pathologies. There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically.

What characterises M.E. every bit as much as the individual symptoms however is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain (the CNS) this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) in M.E. include:

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

There is also:

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

You may also like to try:

*“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.”*

You really might have to have these ones written down of course!

**It might feel awkward to begin with, but when you've tried it out a few times and come up with a description that works for you** and that you can remember, it will soon become second nature. Write it down on something to begin with if you have to!

You may well be surprised by how much more positive and sympathetic the responses you receive are when you talk about real debilitating symptoms instead of mere ‘fatigue’ or ‘low energy’ (which almost everyone thinks they have just as bad too – except they assume they must just cope with it better than you and that you are mentally weak somehow! As if! As if you don’t have to learn how to be stronger than almost anyone just to get through each day with M.E.). Let healthy people try and say they also get occasional paralysis, tremors, orthostatic intolerance or seizures! (or whatever other symptoms you have).

Really educating yourself (and then others) about Myalgic Encephalomyelitis (and the difference between M.E. and ‘CFS’) doesn't hurt either. If you ever get a bad reaction from anyone (not just about not using the 'f' word but about the whole M.E. topic generally) when you tell them about your illness, there is **nothing** better than having lots and lots of hard facts at hand to immediately prove them wrong! I'd highly recommend it.

What is ME?, ME: The Medical Facts and The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List are all available in 2 page summaries that you can print out on a single sheet (double-sided) for easy distribution anywhere, anytime. These first two papers are also now available in a printable small leaflet or business card sized format! Perhaps you could get some small cards professionally printed? Then there is also the ‘One page summary of the facts of M.E.’ and even M.E. vs MS: Similarities and differences. Why not keep a few copies in your wallet, bag, bedside table or glove-box so you are always prepared and never left having to explain the whole complex thing off the top of your head?

More importantly, doing this may also ensure you are also never left having to just put up with some ignorant person spouting offensive absolute nonsense about an illness they know NOTHING about. We have enough to cope with having M.E. without having to put up with that sort of hurtful abuse. Handouts can make such a huge difference to how well you can explain things and how well you are understood or treated. Definitely worth a try at least! Best of luck!

**Permission is given for this document to be freely redistributed** by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author’s attribution) is reproduced in full and without alteration.