

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.

Why care about M.E.?

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The creation of the bogus disease category of ‘Chronic Fatigue Syndrome’ by financial vested interest groups has caused untold suffering to the million or more patients with the neurological disease Myalgic Encephalomyelitis worldwide. Patients are being very unfairly and unethically treated and are being seriously abused and denied their basic human rights (even unto death in some cases).

Significant harm is also caused to the many hundreds of thousands of patients presenting with a vast array of different illnesses involving fatigue as a major symptom that are very often misdiagnosed as ‘CFS’ and so are also denied appropriate diagnosis and treatment.

But it is not just those who have M.E., or that are misdiagnosed with ‘CFS’ who are affected by the ‘CFS’ medical scam. It negatively affects all members of our society.

So why exactly should *you* care about Myalgic Encephalomyelitis and want to help patients achieve the same basic rights as those with similar neurological diseases such as Multiple Sclerosis?

Why should *you* care about whether or not the fictional disease category of ‘CFS’ is abandoned?

1. Because corporations with vested financial interests should not be allowed to determine government policy and to attempt to erase the scientific facts and history of an entire illness merely because it would substantially increase their financial ‘bottom line’ to do so.
2. Because we need government to put science and basic human rights ahead of the financial interests of large corporations that are acting unethically. Government cannot be allowed to completely disregard reality and knowingly participate in the ‘CFS’ lie without ever being seriously challenged. How can this be allowed to happen in our supposedly democratic countries? How can we let it happen?

3. Because your tax dollars are being wasted on bogus 'research' which is being conducted on such a heterogenous (mixed) group of 'CFS' patients that it is extremely unlikely to be to the benefit of any distinct patient group.

This outrageous waste occurs while no money at all is being spent by governments around the world trying to find treatments for M.E. despite it being one of the most disabling and horrific diseases there is, affecting more than a million adults and young children worldwide.

Prior to the invention of "CFS" in 1988, the small resources that went into researching and treating genuine M.E. represented a more ethical, scientifically-supported and helpful approach to patients than we see today.

4. Because significant social wealth is being wasted on 'rehabilitation' programs such as CBT and GET which do nothing for most patients, and which severely harm and permanently disable or kill many M.E. patients. Many of those with severe M.E. are severely affected because of such programs (or other similarly bogusly determined and equally inappropriate medical advice).

This growing trend, particularly in the UK, of devoting significant government funding to treatments which are not only proven to be bogus, but are also known to be actively harmful in many cases, in support of various 'industries' must be opposed. A true *healthcare* industry should have its funding determined by rigorous science and the real needs of patients and their families, rather than by propping up unscientific industries.

5. Because treating our most vulnerable citizens fairly and with respect is the mark of a healthy and democratic society.

6. Because what is happening is deeply wrong. It is systematic abuse and neglect of some of the most vulnerable and innocent members of society. Very ill people are being literally tortured by government and by doctors, and being denied even basic medical care and/or welfare and social support.

7. Because the government is not taking the appropriate measures to protect the blood supply from M.E. A significant percentage of M.E. patients became ill after a blood transfusion, yet only in the UK are those with M.E. specifically banned from donating blood.

8. Because M.E. affects not just the M.E. patient but their whole family. The children of parents with M.E. often pay a high price, and parents of children with M.E. often become their part-time or full-time carers.

9. Because children as young as three get M.E., and their families are currently put through hell. Not only are parents not given access to any type of medical care or even basic information about M.E., but they are often wrongly accused of causing their child's illness to gain attention for themselves (they are falsely accused of Munchausen's by proxy) and may even be charged with this offense, or have their child forcibly removed from their care. The child may then be

subjected to medical torture. (For example, they may be cruelly denied contact with family or access to food, or thrown into swimming pools and so on, in order to force the child to ‘stop *acting* as if they were ill.’)

10. Because people with M.E. are being robbed of their chance for improvement, and are often sentenced to a life of severe disability, for want of the most basic information about their disease and the most basic level of medical care (care which is taken for granted by those with very similar diseases such as MS.

11. Because according to the world’s leading M.E. expert, Dr Byron Hyde, if the M.E. enteroviruses were recovered from patients during their onset illness most or perhaps all cases of M.E, could be PREVENTED in the future ‘by simply adding essential enteroviral genetic material from these enteroviruses to complement polio immunization.’ At the very least, some basic funding should be dedicated towards this investigation if there is a possibility it could prevent hundreds of thousands of patients from contracting such a life-altering and severely disabling lifelong disease.

12. Because nobody is immune from a ‘CFS’ misdiagnosis, and the lack of care and support that comes with it. You or someone you know, or someone you love could very well be next.

Patients with cancer, which often causes significant fatigue, are sometimes told they have ‘CFS’ and so they are denied the life-saving treatment that they need and so they die. Patients with Lyme disease are often told they have ‘CFS’ and so are denied access to the antibiotics that may well have given them their lives back. Patients with simple vitamin deficiencies are often told they have ‘CFS’ and so denied the very simple and effective treatments/cured available for their condition and so suffer needlessly sometimes for many years. The list goes on. There are so many needless deaths, and so much unnecessary suffering and disability due to the misdiagnosis of ‘CFS.’

13. Because nobody is immune from M.E. You or someone you know, or someone you love, could very well be next. M.E. is as common as M.S. and affects all ethnicities around the world, even affecting children as young as three.

M.E. strikes suddenly; a person goes from being healthy to being very ill and disabled over a matter of a day or so. M.E. occurs in epidemic and sporadic forms, with over 60 outbreaks of M.E. being documented worldwide since 1934.

Most importantly of all, you should care because those with M.E. are far too ill to fight for themselves like AIDS sufferers did. AIDS patients also often have an early asymptomatic period of illness, if they are diagnosed early with HIV

infection, which enables significant potential contribution to activism – but for M.E. patients the severe symptoms begin on day one. M.E. patients cannot raise large amounts of money for advocacy like breast cancer charities can.

Many cannot even read basic information about what is happening as they are just too ill, and most families and friends of patients are unwilling to help very often due to ignorance about the political and medical facts of M.E. Indeed very often friends and family members of patients treat the person with M.E. abusively, withhold support and so contribute further to their high level of disability and suffering.

M.E. patients have also been utterly ignored by human rights groups, despite the appalling loss of their most basic human rights and the extreme suffering caused by this to many very severely ill and vulnerable people.

M.E. patients desperately need YOUR help.

How has this abuse of science been allowed to happen?

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

Other groups which benefit include the following:

- a. Governments
- b. The vaccine industry
- c. The chemical industry
- d. Psychiatrists
- e. ‘CFS’ doctors
- f. Medical doctors
- g. The media (including medical journals)
- h. CFS’ or ‘ME/CFS’ (and other) groups that sell vitamins and other supplements to ‘CFS’ patients
- i. CFS’ or ‘ME/CFS’ (etc.) so-called patient support and advocacy groups.

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.

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

Conclusion

Certain groups and individuals are benefiting enormously from this fraudulent artificial 'CFS' construct.

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

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

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

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

Why is almost nobody doing this? Why is the world letting these groups get away with such a heinous scam and such appalling abuse on a massive scale? Why isn't the world caring enough or smart enough or gutsy enough to see through these slick and well-funded misinformation campaigns, and to act? How can this be, when the lies are so flimsy and scientifically laughable?

Have we learned nothing from the devastating corporate cover-ups of the truth about tobacco and asbestos 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.

Where do we go from here?

Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. would achieve nothing and only create yet more confusion and mistreatment. The problem is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually *do* have psychological illnesses. *There is no such distinct disease as 'CFS' – that is the entire issue, and the vast majority of patients misdiagnosed with CFS do not have M.E. and so have no more right to that term than to 'cancer' or 'diabetes.'*

The only way forward, for the benefit of society and every patient group involved, is that:

1. The bogus disease category of 'CFS' must be abandoned completely.

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

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

The term myalgic encephalomyelitis was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO in their International Classification of Diseases (ICD), since 1969. The currently version ICD-10 lists M.E. under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. (2006, [Online])

3. People with M.E. must immediately stop being treated as if they are mentally ill, or suffer with a behavioural illness, or as if their physical symptoms do not exist or can be improved with 'positive thinking' and exercise – or mixed in

with various ‘fatigue’ sufferers in any way or patients with any other illness than authentic Myalgic Encephalomyelitis.

People with M.E. must also be given access to basic medical care, financial support and other appropriate services (including funding for legitimate M.E. research) on an equal level to what is available for those with comparable illnesses (eg. multiple sclerosis or Lupus). The facts about M.E. must again be taught to medical students, and included in mainstream medical journals, and so on.

How you can 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.*

Do offer support to those very few genuine M.E. advocacy groups which exist. (Most notably, The Hummingbirds' Foundation for M.E. (this site), Dr Hyde's The Nightingale Research Foundation, The 25% M.E. Group and RiME.)

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 non-M.E. illnesses misdiagnosed as 'CFS' need your help.

People with M.E. desperately need your help.

Please help if you can.

Acknowledgements: This paper was edited by Virginia Brown. This paper contains a significant amount of material taken from Who benefits from 'CFS' and 'ME/CFS'? written by Jodi Bassett and Lesley Ben.

More information

- See the new paper: M.E. vs MS which explains the many medical similarities and political differences between the two diseases.
- For more information on all aspects of M.E. – including what you can do to help M.E. patients' desperate fight for justice and fair treatment – and for references, please see: What is M.E.? A historical, medical and political overview. See also: Who benefits from 'CFS' and 'ME/CFS'?
- 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.
- The bogus disease category of 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with 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 terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and CFS are very different and distinct, and it is the definitions of each of these terms which is of primary importance. *The distinction must be made between terminology and definitions.*

- People with **chronic fatigue** may be tired because of cancer, Multiple Sclerosis, vitamin deficiency, a sleep disorder, depression or a large

number of other reasons. Fatigue or chronic fatigue is a symptom of many illnesses. Up to 20% of the population may currently suffer from some form of chronic fatigue.

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

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

M.E. can occur in both epidemic and sporadic forms and over 60 outbreaks of the illness have been recorded worldwide since 1934.

M.E. can be extremely disabling and in some cases the illness is fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

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

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

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

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

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

Dr Melvin Ramsay on Myalgic Encephalomyelitis: *"The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in*

another way, those patients who are given a period of enforced rest from the onset have the best prognosis."

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

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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



- 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.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

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

However, the hearts of M.E. patients only pump barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.

If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.

M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.

- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: What is M.E.? Extra extended version. Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.