

**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.*

**M.E. vs M.S. – Condensed/modified version**

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As many members of the public and the medical profession will be aware, Multiple Sclerosis (MS) is a disabling neurological disease which also affects the muscles. MS is a terrible disease and can cause severe disability and extreme suffering.

However, as surprising or bizarre as it seems, there is a section of the community which has reason to be very ENVIOUS of people who have MS. It is made up of people who have the disabling neurological disease called Myalgic Encephalomyelitis (M.E.)

**Medical similarities between MS and M.E.**

The reason M.E. patients are envious is not so much because of the type of illness MS is medically compared to M.E. M.E. and MS are actually very similar medically in many ways, as the following list demonstrates.

**Table 1. Medical similarities between MS and M.E.**

<b>Multiple Sclerosis</b>	<b>Myalgic Encephalomyelitis</b>
MS is primarily a neurological disease, i.e. a disease of the central nervous system (CNS).	M.E. is primarily a neurological disease, i.e. a disease of the central nervous system (CNS).
Demyelination (damage to the myelin sheath surrounding nerves) has been documented in MS.	Demyelination (damage to the myelin sheath surrounding nerves) has been documented in M.E.
Evidence of oligoclonal bands in the cerebrospinal fluid has been documented in MS.	Evidence of oligoclonal bands in the cerebrospinal fluid has been documented in M.E.
No single definitive laboratory test is yet available for MS but a series of tests are available which can objectively confirm the diagnosis with some certainty.	No single definitive laboratory test is yet available for M.E. but a series of tests are available which can objectively confirm the diagnosis with a high degree of certainty.
MS can be severely disabling and cause significant numbers of patients to be bedbound or wheelchair-reliant.	M.E. can be severely disabling and cause significant numbers of patients to be bedbound, wheelchair-reliant or housebound.
MS can be fatal (either from the disease itself or from complications arising from the disease)	M.E. can be fatal (either from the disease itself or from complications arising from the disease)
MS significantly reduces life expectancy.	M.E. significantly reduces life expectancy.
Symptoms/problems which occur in MS include: impaired vision, nystagmus, afferent pupillary defect, loss of balance and muscle coordination, cogwheel movement of the legs, slurred speech, difficulty speaking (scanning speech and slow hesitant speech), difficulty writing, difficulty swallowing, proprioceptive dysfunction, abnormal sensations (numbness, pins and needles), shortness of breath, headaches, itching, rashes, hair loss, seizures, tremors, muscular twitching or fasciculation, abnormal gait, stiffness, subnormal temperature, sensitivities to common chemicals, sleeping disorders, facial pallor, bladder and bowel	Symptoms/problems which occur in M.E. include: impaired vision, nystagmus, afferent pupillary defect, loss of balance and muscle coordination, cogwheel movement of the legs, slurred speech, difficulty speaking (scanning speech and slow hesitant speech), difficulty writing, difficulty swallowing, proprioceptive dysfunction, abnormal sensations (numbness, pins and needles), shortness of breath, headaches, itching, rashes, hair loss, seizures, tremors, muscular twitching or fasciculation, abnormal gait, stiffness, subnormal temperature, sensitivities to common chemicals, sleeping disorders, facial pallor, bladder and bowel

problems, difficulty walking, pain, tachycardia, stroke-like episodes, food intolerances and alcohol intolerance, and partial or complete paralysis.	problems, difficulty walking, pain, tachycardia, stroke-like episodes, food intolerances and alcohol intolerance, and partial or complete paralysis.
MS can cause orthostatic intolerance (dizziness or faintness on standing).	M.E. commonly causes severe orthostatic intolerance (which often worsens to become severe POTS and/or NMH).
Short-term memory loss and other forms of cognitive impairment occur in 50% of MS patients. 10% of MS patients have cognitive impairments severe enough to significantly affect daily life.	Short-term memory loss and other forms of cognitive impairment occur in 100% of M.E. patients. Almost all M.E. patients have cognitive impairments that significantly affect daily life.
MS patients often become severely more ill in even mildly warm weather. Cold weather can also cause significant problems.	M.E. patients often become severely more ill in even mildly warm weather. Cold weather can also cause significant problems.
MS is thought to cause a breakdown of the blood brain barrier.	M.E. is thought to cause a breakdown of the blood brain barrier.
MS can affect autonomic nervous system function (including involuntary functions such as digestion and heart rhythms).	M.E. can affect autonomic nervous system function (including involuntary functions such as digestion and heart rhythms).
A positive Babinski's reflex is consistent with several neurological conditions, including MS.	A positive Babinski's reflex (or extensor plantar reflex) is consistent with M.E.
The Romberg test will often be abnormal in MS. (This test measures neurological dysfunction.)	The Romberg test will be abnormal in 95% or more of M.E. patients.
An abnormal neurological exam is usual in MS. Abnormalities are also commonly seen in neuropsychological testing in MS.	An abnormal neurological exam is usual in M.E. Abnormalities are also commonly seen in neuropsychological testing in M.E.
MS causes a certain type of brain lesion detectable in MRI brain scans. Abnormalities are also seen in EEG and QEEG brain maps and SPECT brain scans in MS.	M.E. causes a certain type of brain lesion detectable in MRI brain scans. Abnormalities are also seen in EEG and QEEG brain maps and SPECT brain scans in M.E.
Hypothyroidism is found in many MS patients.	Hypothyroidism is found in almost all M.E. patients.
The glucose tolerance test is often abnormal in MS.	The glucose tolerance test is often abnormal in M.E.
Low blood pressure readings (usually low-normal) are common in MS.	Low blood pressure readings are extremely common in M.E. Severely low blood pressure readings as low as, or lower than, 84/48 are common in severe M.E. or those having severe relapses. This can occur at rest or as a result of orthostatic or physical overexertion. Circulating blood volume measurements of only 50% to 75% of expected are also commonly seen in M.E.
Patients with MS have an increased risk of dying from heart disease or vascular diseases.	Deaths from cardiac problems are one of the most common causes of death in M.E.
Although MS is primarily neurological, it also has aspects of autoimmune disease.	Although M.E. is primarily neurological, it also has aspects of autoimmune disease.
MS usually affects people between the ages of 20 and 40 years, and the average age of onset is approximately 34 years. Onset occurs between the	The average ages affected by M.E. are similar to those seen in MS. However, the average age of onset may be significantly younger in M.E.

ages of 20 to 40 years in 70% of patients.	
MS was once thought to be rare in children, but we know that around 5% of MS sufferers are under 18.	Around 10% of M.E. sufferers are under 18.
MS affects more than a million adults and children worldwide.	M.E. affects more than a million adults and children worldwide.

As well as there being many similarities in symptoms, the brain scans from M.E. and MS patients are often very similar, as this chart illustrates. MS and M.E. both cause a certain type of brain lesion detectable in brain scans. Those with MS tend to have fewer brain lesions of a larger size, while M.E. is associated with a greater number of these lesions of a somewhat smaller size.

M.E. and MS are so similar medically that they are sometimes misdiagnosed as one another.

The names used for M.E. and MS also indicate the similarities between the two diseases. MS was first described in 1868, and MS has also been known as ‘disseminated sclerosis’ or ‘**encephalomyelitis** disseminate.’ Myalgic Encephalomyelitis has existed for centuries but was first comprehensively scientifically documented in 1934, when an outbreak of what at first seemed to be poliomyelitis (polio) occurred in Los Angeles (M.E. occurs in outbreaks as well as sporadically). The term Myalgic Encephalomyelitis was coined in 1956. Earlier names for M.E. include ‘atypical polio’ and atypical **multiple sclerosis**.’

Both MS and M.E. have been correctly classified as organic diseases of the central nervous system in the World Health Organization’s International Classification of Diseases for many decades. MS is classified at G 35 and M.E. at G 93.3.

**Why are people with M.E. often envious of people with MS?**

MS and M.E. are distinct diseases, but they are in many ways very similar medically. However, despite the medical similarities, the two diseases are treated very differently politically and socially. The differences between the political and social treatment of MS and M.E. are the reason for M.E. patients’ envy of MS sufferers.

**Table 2. Political and social differences between the treatment of MS and M.E.**

<b>Multiple Sclerosis</b>	<b>Myalgic Encephalomyelitis</b>
MS is a neurological disease, so MS patients are treated primarily by neurologists. In countries such as Australia, Canada, New Zealand, the USA and the UK, the majority of MS patients have access to a neurologist who is knowledgeable about MS.	M.E. is also a neurological disease that is appropriately treated by a neurologist, yet very few M.E. patients have access to a doctor who knows even the most basic facts of M.E., let alone access to a neurologist who has experience and knowledge of M.E. The vast majority of M.E. patients have no access to appropriate medical care at all.
Media reports on MS are of a high standard. If reporters put out stories about MS that were not factual, there would be a public outcry and then an apology made.	Media reports on M.E. are of a very low standard. It is extremely common to read articles claiming to be about M.E. but which do not contain even one accurate fact about the disease. Complaints made by M.E. patients and experts are ignored.
Media reports on those who have experienced some recovery from MS, involve genuine MS patients.	Media reports of ‘miracle recoveries’ from M.E. touting one pseudo-treatment or another are very common. However, the patients described did not have M.E. (or any other serious neurological disease).
MS advocacy groups do good work for MS patients and help raise awareness and funds for research. MS groups are run for and by MS patients.	The vast majority of M.E. advocacy groups do not advocate on behalf of M.E. patients but instead work directly against the best interests of M.E. patients. The vast majority of these groups and <b>not</b> run for or by M.E. patients, and their agendas are <b>not</b> helping M.E. patients. These groups often distribute information on M.E. which is completely

	inaccurate and which also belittles and misrepresents M.E. patients.
MS charities would never support treatments for MS which had zero chance of success, and which very often caused a severe and prolonged deterioration of the patient, or even death.	So-called M.E. charities very often fully support and push 'treatments' for M.E. which have zero chance of success, and which very often cause a severe and prolonged deterioration of the patient, or even death.
MS is a well-known illness, thus patients are in general treated appropriately by doctors and other medical staff.	M.E. is an illness that most medical staff are not well educated about. M.E. patients are often treated inappropriately by doctors and other medical staff.
People with MS will generally qualify for the appropriate welfare and medical insurance payouts they are entitled to.	People with M.E. are very often denied the appropriate welfare and medical insurance payouts they are entitled to.
MS receives many millions of dollars in government funding for research, and millions more are raised each year by the big MS charities around the world.	M.E. receives no government funding worldwide, and very little is raised by M.E. charities. What little is raised by these groups is virtually always spent researching non-M.E. patient groups or mixed patient-groups, but even those studies which do include a small proportion of M.E. patients are useless as mixed patient groups make any results meaningless.
When research says it involves MS patients one can have a high degree of confidence that this is indeed the case.	When research says it involves M.E. patients one can only have a very low degree of confidence that this is indeed the case.
When a patient with MS chooses euthanasia, public sympathy is expressed for the degree of pain and suffering that must have led to such a choice.	When a patient with M.E. chooses euthanasia, public derision is often expressed. Even when, as is almost always the case with euthanasia, the person with M.E. was severely affected and bedbound, it is very often blithely claimed by the media either that the patient was not ill at all, or had a mild disease that could be easily cured within weeks <i>if the patient only truly wanted to get better.</i>

Although MS and M.E. are very similar medically, they are worlds apart politically and socially.

### **Why is the public perception so different with M.E. as compared to MS?**

The public perception of MS reflects the reality. Most members of the public are aware of the basic facts: that MS is a neurological disease affecting the muscles, and that it can be very disabling or fatal. Understanding of these facts is also reflected in the way the media handles MS, government policy on MS, and so on.

The public perception of M.E. could not be further removed from the medical reality of the disease.

Most members of the public, if they have heard of M.E., have heard only an entirely inaccurate account of the disease which they mistakenly believe to be based on science. Despite the fact that M.E. is a serious neurological disease comparable to MS, Lupus and polio, M.E. is seen by most of the public and even by most of the medical profession most often as 'trivial.' M.E. is perceived and presented similarly by most of the media and by government. M.E. patients are treated utterly differently to those with comparable diseases such as MS. The contrast is stark.

There is an abundance of evidence showing that MS is an organic neurological disease that can be severely disabling or fatal. The same is true of M.E. The evidence supporting M.E. is no less compelling, although you would not know this from the way M.E. is dealt with. If anything M.E. has more scientific credibility; it is far easier to diagnose due to its acute onset and more obvious, systemic and unique pathology; the cause is far more certain in M.E., and so on.

In short, the reason M.E. is treated so differently than MS despite them being comparable diseases has nothing to do with science or evidence, and everything to do with MONEY.

M.E. patients are being (mis)treated based purely on mere financial considerations. Financial vested interest groups have subverted and obscured the reality of M.E. for their own benefit. Many millions of dollars are being made (or saved) by powerful medical insurance companies, and others, by this scam. (This is explained in detail in [What is Myalgic Encephalomyelitis? A historical, medical and political overview.](#))

This abusive money-making fiction about M.E. is widely accepted in the community, but it has about as much to do with science as astrology has to astronomy. It had been scientifically disproven hundreds of times over, including before the massive cover-up/scam was even created.

Repeating a lie over and over again will never make it true, but it seems it often will make lots of people believe it to be true, especially if the sources are seen as ‘authorities.’ **Which is why this abusive and unscientific money-making fiction about M.E. has continued for 20 years now and has only becomes more extreme and entrenched over time.**

MS is not being targeted in the same way as M.E. by insurance companies etc. This is a matter of timing: MS emerged earlier, received more medical attention and has been longer established within mainstream medicine than M.E. Because of this fortunate timing difference, MS has escaped the modern manipulation for profit which has plagued M.E. for the last 20 years.

For example, doctors working for medical insurance companies are also able to get influential government advisory positions in the field of health which play a large role in determining how diseases are treated, categorized and even defined. Giving corporations with vested interests the power to unscientifically ‘re-define’ and/or re-classify (i.e. wrongly re-classify) a disease to suit their own interests can be *immensely* lucrative for them. Mere political influences have determined how M.E. is dealt with and how it is perceived, which is not true of MS.

Why M.E. patients are so poorly and inappropriately treated is clear. How to stop this abuse when so many groups that are supposed to be there to protect patient rights – government, so-called M.E. charities and the media etc. – are colluding in a cover-up for their own benefit is far less clear unfortunately.

How patients with M.E. can do this and work to change the situation when they are so very ill and disabled, and when so many are too ill to even be able to read the basic facts about what is happening, and when they have so little other support, is not clear. How can patients with M.E. get through to the vast majority of the public who refuse to believe government and industry could be so immoral (despite ample examples of past transgressions)? How can patients with M.E. convince others of the truth when so many seemingly benign companies, government departments, journalists or supposedly patient-based organisations are producing so much completely mutually supportive and superficially convincing propaganda?

These are hard questions and simply enormous problems which M.E. patients are forced to deal with, and which MS patients need not ever consider.

### **M.E. patients sometimes wonder how their lives would be different if they instead had MS...**

People with M.E. wonder if those with MS know how lucky they are to be able to go to the emergency room when they are very unwell, and in fear of dying, and know that they will be treated with respect and given the appropriate care; rather than laughed at, mocked in front of the other patients, refused tests or treatment and just sent home. M.E. sufferers wonder if MS patients know how lucky they are that millions of dollars are being spent trying to cure their disease. That knowledge must be so comforting.

People with M.E. wonder if those with MS know how lucky they are to have access to a doctor who knows at least the basic facts of their disease and how to treat it. Very few patients with M.E. have such a ‘luxury.’ Some M.E. patients wonder if MS patients know how lucky they are to not have to worry that the latest unscientific study or article that claims to be about their disease will cause those around them to mistreat them due to the study either involving an entirely different and unrelated patient group, or being done by those who routinely skew results to suit their own vested interests, or both. The list goes on and on.

MS can be very severe. So can M.E. Being severely ill is hard, but being severely ill through mistreatment, apathy and neglect – as is the case with many severe M.E. patients – is even harder to deal with.

Severe injury (or death) is inflicted on thousands of people with M.E. by inappropriate medical advice every year, but this does not seem to cause any public concern. There would be outrage if even a tiny fraction of the harm done to M.E. patients was done to people with other diseases, but the outrage is just not there for us. For M.E. patients *that* is very, very hard to live with.

It is also hard for M.E. patients to live with the fact that some people with M.E. are reduced to such poverty by refusal of welfare or insurance payments, which they would have received if they had had MS, that they have had

to go to rubbish bins to search for food. That some people with M.E. have died from inappropriate and extremely cruel medical mistreatment, and their abusers will never be brought to justice. That some M.E. patients have had their whole family or all of their friends disown them due to misconceptions about M.E. That some M.E. patients have their rights taken away, and are forced to participate in treatments that cannot improve their condition but which carry an enormous risk of worsening the disease seriously, or causing death. That some parents of kids with M.E. have been charged with causing their kids' illness (falsely accused of Munchausen's by proxy) and had their kids removed from their care and then seriously medically abused. That small children very ill with M.E. have been thrown in swimming pools (and very nearly drowned), or denied food or contact with family, in order to try to force them to do the things that they are too ill to do because of their disease.

M.E. is one of the most severely disabling and devastating diseases there is. Yet despite all the medical advances in today's high-tech world, it is as though M.E. patients live in another era and receive only the most primitive and rudimentary care – if indeed they receive any care at all.

### Conclusion

People will often say to M.E. patients 'at least you don't have MS. It could be worse, you should be grateful.' But if anything the opposite is true. Taking everything into account, the physical reality of each disease plus the misconceptions and abuse surrounding M.E., it is very hard to see how *anyone* would ever choose M.E. over MS, if such a choice were possible.

That isn't to say that MS isn't an horrific and terrible disease, or that those with MS have any more resources or funding than they rightly deserve and need, or that everyone with MS always gets every service they need easily and will always have a very supportive family. *Of course not.* The point is that it just makes no sense that patients with these two very similar diseases are treated so utterly differently just because of political manipulation for profit. That scientific reality, ethics and logic count for so little.

It is as bizarre and unfair as if those with **broken arms** were given x-rays and had the broken bone set and put in a cast until it had healed and so on, while those with **broken legs** were told to go home and stop wasting the doctor's time, or that perhaps taking up jogging would make them feel better.

MS is a severely disabling neurological disease that causes a high degree of suffering. So is M.E. However, there is a whole other world of suffering experienced by M.E. patients which is unknown to MS patients and others with diseases where the public perception and political treatment of the disease is closely aligned with the medical reality. It is an additional type of suffering which can be as much of an additional burden as the disease itself. When you combine these political problems with a disease as severe as M.E., it makes having M.E. one of the worst hells on earth.

The treatment of people with M.E. must be based on science at last, as is the treatment of MS patients. All M.E. patients want is to be treated the same way as those with MS and those with other comparable illnesses. All M.E. patients want is for studies on M.E. to actually involve M.E. patients, for the term M.E. to only be permitted to be used to describe actual M.E. patients, for the facts about M.E. to be taught at medical schools in the same way MS facts are, for appropriate money to be made available for M.E. research, for government policy on M.E. to reflect the reality of M.E., and for the media (including medical journals) to write articles about M.E. with the same standard of factual accuracy as articles are written on MS, and so on.

These things don't seem much to ask for in this day and age. But right now, they are so far away from M.E. patients and if anything they get further and further away as each year passes.

### More information

- For more information on all aspects of M.E. – including what you can do to help M.E. patients' fight for justice and fair treatment – please see: [What is Myalgic Encephalomyelitis? A historical, medical and political overview.](#))
- For more information on this topic, including a table describing the medical differences between MS and M.E. please see the full-length version of this text. (This version of the text also includes information from individual case studies, including that of the author.)
- To be clear, while M.E. can be far more disabling than MS and some aspects of it are worse than is seen in MS, there is also no doubt that some aspects of MS are worse than some aspects of M.E. Please note that none of these charts is designed to be comprehensive or detailed enough to be used to differentiate between a MS or a M.E. diagnosis. They merely provide a very brief overview of this topic. For more information on the diagnosis of M.E. see: [Testing for Myalgic Encephalomyelitis](#)

## References

This paper, like all the papers by me (Jodi Bassett) on this site, merely provides a brief summary of some of the most important facts of Myalgic Encephalomyelitis. A list of, or links to, references to original texts is given at the end of each paper, and these references are very highly recommended as essential additional reading for anyone with a real interest in Myalgic Encephalomyelitis. For further information on the references used on this site, and to read the reference list for this paper, see the [References](#) page and [What is Myalgic Encephalomyelitis? A historical, medical and political overview](#). Additional online resources on Multiple Sclerosis used in creating this paper are listed in the full-length version of this text.

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## Relevant quotes

*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 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

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

Dr Elizabeth Dowsett

*Possible costing for ME support has been based on 3 times the cost of maintenance for multiple sclerosis on the supposition that ME is [up to] 3 times as common. The only costs that we can be sure of are those derived from the failure of appropriate management, and of inappropriate assessments which waste vast sums of money and medical time while allowing patients to deteriorate unnecessarily.*

*Research workers must be encouraged and appropriately funded to work in this field. However they should first be directed to papers published before 1988, the time at which all specialised experience about poliomyelitis and associated infections seem to have vanished mysteriously!*

Dr Elizabeth Dowsett

*The body, its systems (such as the gastrointestinal system, the muscular system, the endocrine system, the cardiovascular and vascular systems) and its organs are dependent and their actions largely controlled by the brain. If the brain is physiologically injured, then so is the body. Depending upon which parts of the brain are physiologically injured different parts of the body will also be caused to malfunction.*

Dr Byron Hyde 2006

*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

*The term "Myalgic encephalomyelitis" (M.E.) was henceforth used in the UK, Canada and Australasia to define an illness which, following a virus infection, leads to multisystem involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs but which is primarily due to central nervous system dysfunction and subsequent breakdown in bodily homeostasis. Confirmation of this hypothesis was supported by electrical tests of muscle and of brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays.*

Dr Elizabeth Dowsett

From Charles M Poser MD in the book The Clinical and Scientific Basis of Myalgic Encephalomyelitis edited by Dr Hyde (paraphrased by the author):

*There are many clinical and laboratory similarities in M.E. and MS, but what separates them is: the plethora of systemic manifestations in M.E., the orthostatic tachycardia seen in M.E., the outbreaks of M.E., the striking involvement of muscle in M.E. and the muscle pathology seen in M.E., the characteristic myalgias and arthralgias in M.E., and the symptoms such as cold extremities and flu-like symptoms etc. seen in M.E. These features are not seen in MS and their presence may even preclude a MS diagnosis.*

*On the lack of funding given to legitimate M.E. research, Dr Byron Hyde M.D. writes: Without heed, we are sitting on the edge of a cliff, waiting for disaster. For many sufferers of M.E. that disaster is already here, and few are listening.*

The Clinical and Scientific Basis of ME p. 115

*The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, those patients who are given a period of enforced rest from the onset have the best prognosis.*

Dr Melvin Ramsay

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

Professor Malcolm Hooper 2006

*There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised.*

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

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



- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease with the ICD code G.93.3.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.
- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.  
However, the hearts of M.E. patients only pump barely enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.  
This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.  
If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.  
*M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*
- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

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