

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.

The HFME 3 part M.E. ability and severity scale

(Modified version)

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Taken from www.hfme.org



THE HFME	
3 PART M.E. ABILITY & SEVERITY SCALE: PART 1 – PHYSICAL ABILITY SCALE	
COMPILED BY JODI BASSETT, 2005. TAKEN FROM WWW.HFME.ORG	
FULLY RECOVERED	
100%	An unrestricted (pre-illness) level of physical activity is possible.
VIRTUALLY RECOVERED	
95%	A high level of physical activity is possible, around 95% of pre-illness capabilities. Able to cope physically with full-time study or work without difficulty, plus enjoy a full and active social life.
MILDLY AFFECTED	
90%	A high level of physical activity is possible, around 90% of expected. Minimal restrictions apply for activities involving exertion only. Able to work full time with difficulty in jobs requiring exertion.
80%	Physical activity is at around 80% of expected, a daily activity limit is clearly noted. Unable to work full-time in jobs requiring physical exertion, but able to work full-time in lighter activities if hours are flexible. Social activities requiring physical exertion may be difficult.
MODERATELY AFFECTED	
70%	Physical activity is at around 70% of expected. Unable to perform strenuous tasks without difficulty, but able to work part-time in light activities or deskwork for 5 – 7 hours a day, although rest periods are required. Physical abilities degenerate significantly with sustained exertion.
60%	Physical activity is at around 60% of expected. Unable to perform strenuous tasks, but able to work part-time in light activities or deskwork for 5 - 6 hours a day if requirements for quiet and resting are met. Physical abilities degenerate significantly with sustained exertion. Physically undemanding social activities are possible.
50%	Physical activity is at around 50% of expected. Unable to perform strenuous tasks, but able to work part-time in light activities or deskwork for 4 - 5 hours a day if requirements for quiet and resting are met. Physical abilities degenerate significantly with sustained exertion. Physically undemanding social activities are possible.
MODERATE TO SEVERELY AFFECTED	
40%	Overall activity level reduced to around 40% of expected. May be unable to walk without support much beyond 100/200m, a walking stick or wheelchair may be used to travel longer distances. 2 – 4 hours of deskwork may be possible each day if requirements for quiet and resting are met. Physically undemanding social activities are possible.
30%	Overall activity level reduced to around 30% of expected. May be unable to walk without support much beyond 100/200m, a walking stick or wheelchair may be used to travel longer distances. Several hours of deskwork may be possible each day if requirements for quiet and resting are met. Physically undemanding social activities are possible.
20%	Overall physical activity level reduced to around 20% of expected. Not confined to the house but may be unable to walk without support, much beyond 50/100m, a wheelchair may be used to travel longer distances. Requires 3 or 4 regular rest periods during the day, only one 'large' activity possible per day usually requiring a day or more of rest in-between.
SEVERELY AFFECTED	

10%	Overall physical activity level reduced to around 10% of expected. Usually confined to the house but may occasionally (and with a significant recovery period) be able to take a short wheelchair ride or walk, or be taken to see a doctor. Most of the day needs to be spent resting except for a period of several hours interspersed throughout the day when small tasks may be completed (or one larger one). Activity is mostly restricted to managing the tasks of daily living and some assistance with or modification of tasks is often required.
5%	Overall physical activity level reduced to around 5% of expected. Usually confined to the house but may very occasionally (with a recovery period of a week or more) be able to take a short wheelchair ride or walk, or be taken to see a doctor. Bedbound or couch-bound for 21+ hours a day. Activity is restricted almost exclusively to managing the tasks of daily living and some assistance with or modification of tasks is necessary.
VERY SEVERELY AFFECTED	
A	Overall physical activity level severely reduced. No travel outside the house is possible. Bedbound the majority of the day (22+ hours) but may (with difficulty and an exacerbation of symptoms) be able to sit up, walk or be pushed in a wheelchair for short periods/distances interspersed throughout the day (to the bathroom or to travel from room to room). Almost all tasks of daily living need to be done by others and/or heavily modified. Eating may be very difficult.
B	Overall physical activity level very severely reduced. No travel outside the house is possible. Close to completely bedbound (lying flat in bed 23.5+ hours a day). May sometimes (with difficulty and with an exacerbation of symptoms) be able to sit up, walk or be pushed in a wheelchair for very short periods/distances interspersed throughout the day (to the bathroom or to travel from room to room). All tasks of daily living need to be done by others and/or very heavily modified. Eating and drinking may be very difficult.
EXTREMELY SEVERELY AFFECTED	
C	Completely bedbound and may be unable to turn or move in bed (or at all) unassisted. Eating is extremely difficult and liquid food may be necessary (little and often). Swallowing liquids may also be difficult or impossible and in some cases nasal-feeding tubes may be required. Unable to care for oneself at all. Bed-baths (and other personal care tasks) undertaken by a carer or family member may cause severe relapses in symptoms and so only be able to be attempted occasionally.

THE HFME	
3 PART M.E. ABILITY & SEVERITY SCALE	
PART 2 – COGNITIVE ABILITY SCALE	
COMPILED BY JODI BASSETT, 2005. TAKEN FROM WWW.HFME.ORG	
FULLY RECOVERED	
100%	An unrestricted (pre-illness) level of cognitive functioning is possible.
VIRTUALLY RECOVERED	
95%	A high level of cognitive functioning is possible, around 95% of what was possible pre-illness. Able to cope on a cognitive level with full-time study or work without difficulty, plus enjoy a full social life.
MILDLY AFFECTED	
90%	A high level of cognitive functioning is possible, around 90% of expected. Minimal restrictions apply for activities which demand a high standard of cognitive functioning only. Unable to manage full-time study or work without difficulty in jobs which are excessively demanding on a cognitive level.
80%	Cognitive functioning is at around 80% of expected, a daily cognitive activity limit is clearly noted. Unable to work full-time in jobs that are demanding on a cognitive level, but can work full-time in less demanding jobs if hours are flexible. Some restrictions on social life.
MODERATELY AFFECTED	
70%	Cognitive functioning is at around 70% of expected. Unable to perform tasks which are excessively demanding on a cognitive level, but can complete lighter activities for 4 – 7 hours a day although rest periods are required. Cognitive functioning degenerates significantly in a crowded, noisy or busy environment or with sustained and/or high level use. Social life may be moderately affected.
60%	Cognitive functioning is at around 60% of expected. Unable to perform tasks which are excessively demanding on a cognitive level, but able to work part-time in lighter activities for 4 - 5 hours a day (or perhaps longer at a reduced quality level) if requirements for quiet and resting are met. Cognitive functioning degenerates significantly in a crowded, noisy or busy environment or with sustained and/or high level use. Quiet, non-mentally challenging social activities possible.

50% Cognitive functioning is at around 50% of expected. Unable to perform tasks which are excessively demanding on a cognitive level, but able to work part-time in lighter activities for 3 - 4 hours a day (or perhaps longer at a reduced quality level) if requirements for quiet and resting are met. Cognitive functioning degenerates significantly in a crowded, noisy or busy environment or with sustained and/or high level use. Quiet, non-mentally challenging social activities possible.

40% Cognitive functioning is reduced to around 40% of expected. Unable to perform mentally challenging tasks, but able to complete simpler cognitive tasks (study or work) for 2 -3 hours a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration and cognitive ability are significantly affected. Following the plots of TV shows or books may be difficult. Non-mentally challenging social activities possible on a limited basis.

MODERATE TO SEVERELY AFFECTED

30% Cognitive functioning is reduced to around 30% of expected. Unable to perform mentally challenging tasks, but able to complete simpler cognitive tasks (study or work) for 1 - 2 hours a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration and cognitive ability are significantly affected. Following the plots of TV shows or books may be difficult. Non-mentally challenging social activities possible on a limited basis.

20% Cognitive functioning is reduced to around 20% of expected. Unable to perform mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for 30 minutes to 1 hour a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are significantly affected. Following the plots of TV shows or books may be difficult. Non-mentally challenging social activities possible on a limited basis.

SEVERELY AFFECTED

10% Cognitive functioning is reduced to around 10% of expected. Unable to perform mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for 30 minutes a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are significantly affected at all times and may be severely affected during relapses. Concentration for more than half an hour at a time may be extremely difficult. Following the plots of TV shows or books may be difficult or impossible. Non-mentally challenging social activities possible on a very restricted basis.

5% Cognitive functioning is reduced to around 5% of expected. Unable to perform even moderately mentally challenging tasks easily or often, but able to complete less complex cognitive tasks for 15 – 30 minutes or so a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are significantly affected at all times and may be severely affected during relapses. Concentration for more than 10 to 15 minutes at a time may be extremely difficult. Following the plots of TV shows or books may be difficult or impossible. Non-mentally challenging social activities possible occasionally for short periods.

VERY SEVERELY AFFECTED

A Cognitive functioning is reduced to less than 5% of expected. Able to complete simple cognitive tasks for 10 – 20 minutes or so a day (or perhaps longer at a lower quality level) if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are severely affected. Concentration may be extremely difficult. Only short periods of TV, radio or reading are possible. A friend can be seen for 10 - 30 minutes once a week or so.

B May be able to complete simple cognitive tasks such as talking, listening to speech or reading (with difficulty) for several 2 – 10 minute periods throughout the day if requirements for quiet and resting are met. Concentration, memory and other cognitive abilities are very severely affected. Concentration may be extremely difficult. There may be an inability to maintain full consciousness throughout the day. No TV is possible but quiet music or an audio book may be listened to for short periods. A friend can be seen for a few minutes.

EXTREMELY SEVERELY AFFECTED

C Concentration, memory and other cognitive abilities are extremely severely affected. Achieving even a low level of concentration may be extremely difficult or impossible and there may be a high degree of cognitive confusion as a result. No TV or radio is possible. There may also be a difficulty maintaining consciousness for more than a few moments or minutes at a time. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. Reading or writing more than the occasional few words is often impossible.

THE HFME	
3 PART M.E. ABILITY & SEVERITY SCALE	
PART 3 – SYMPTOM SEVERITY SCALE	
COMPILED BY JODI BASSETT, 2005. TAKEN FROM WWW.HFME.ORG	
FULLY RECOVERED	
100%	No symptoms
VIRTUALLY RECOVERED	
95%	No symptoms at rest. Mild symptoms on occasion following strenuous physical or mental activity but recovery is complete by the next day.
MILDLY AFFECTED	
90%	No symptoms at rest. Mild symptoms (1 – 3/10) for several hours or days following strenuous physical or mental activity.
80%	Mild symptoms (1 – 3/10) at rest, worsened to mild/moderate (4 or 5/10) for several hours or days following strenuous physical or mental activity beyond the person's limits.
MODERATELY AFFECTED	
70%	Mild - mild/moderate symptoms (1 - 5/10) at rest, worsened to moderate (6 or 7/10) for several hours or days following physical or mental activity beyond the person's limits.
60%	Mild/moderate symptoms (4 or 5/10) at rest. There is mild/moderate pain and/or sensations of illness/dysfunction throughout the body and brain for some parts of the day. Increasing moderate symptoms (6 or 7/10) for several hours, days or weeks following physical or mental activity beyond the persons limits.
MODERATE TO SEVERELY AFFECTED	
50%	Moderate symptoms (6 or 7/10) at rest. There is moderate pain and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day. Increasing moderate (and occasionally severe – 8/10) symptoms for several hours, days or weeks following physical or mental activity beyond the persons limits which may persist for hours, days or a week or more afterward.
40%	Moderate (6 or 7/10) and occasionally severe (8/10) symptoms at rest. There is moderate pain (6 or 7/10) and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day. Increasing moderate and sometimes severe symptoms for several hours, days or several weeks or more following physical or mental activity beyond the persons limits.
30%	Moderate (7/10) and occasionally severe (8/10) symptoms at rest. There is moderate pain (7/10) and/or sensations of illness/dysfunction throughout the body and brain for significant periods of the day. Increasing moderate and sometimes severe symptoms for several hours, days or several weeks or months or more following physical or mental activity beyond the persons limits.
SEVERELY AFFECTED	
20%	Moderate to severe symptoms (6 – 8/10) at rest. There is moderate to severe pain (6 – 8/10) and/or sensations of illness/dysfunction throughout the body and brain for much of the day. Severe symptoms (8/10) following any physical or mental activity with a recovery period of hours, days or several weeks or months or more. It is all the person can do to just get through one day at a time.
10%	Severe symptoms (8/10) at rest and following even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. There is severe pain (8/10) and/or overwhelming sensations of illness/dysfunction throughout the body and brain for all but a few hours of the day. In some patients only small amounts of stimulus can be tolerated for short periods a few times a day. It is all the person can do to just get through the day a few hours at a time.
VERY SEVERELY AFFECTED	
A	There is severe pain (8/10) and/or overwhelming sensations of illness/dysfunction throughout the body and brain for all but a few short periods in the day – worsened to increasing severe or very severe symptoms (8 or 9/10) following even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. In some patients only small amounts of stimulus can be tolerated for short periods. It is all the person can do to just get through the day one hour at a time.

B	There is severe pain (8/10) and/or overwhelming sensations of illness/dysfunction throughout the body and brain almost continually - worsened to very severe (9/10) or extremely severe (10/10) following even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. In some patients any type of stimulus is intolerable, even very low levels of light, noise, movement and motion are excruciating for more than very short periods. The smallest physical movements bring extreme exacerbations in symptoms. Intellectual activity is similarly affected. It is all the person can do to just get through the day one minute at a time.
EXTREMELY SEVERELY AFFECTED	
C	There is very severe (9/10) pain and/or overwhelming sensations of illness/dysfunction throughout the body and brain <i>continually</i> - worsened to extremely severe (10/10) by even trivial physical or mental activity with a recovery period of hours, days or several weeks or months or more. In some patients any type of stimulus is intolerable, even very short/low exposures to light, noise, movement and motion are excruciating and may require a long recovery period. The smallest physical movements bring intense exacerbations in symptoms. Mental activity is similarly affected. It is all the person can do to just get through the day one second at a time.

These scales are designed to be used by Myalgic Encephalomyelitis sufferers to measure improvements and changes over different aspects of their illness over time. These scales are not intended for medical use, I am not a medical doctor.

The scale is in three parts because cognitive abilities, physical abilities and symptom severity are often not all be equally affected in each patient. A scale with more than one category should ensure greater accuracy and also hopefully be more encouraging as there is a greater likelihood that patients will score a bit higher in at least one category compared to the other two.

Some suggestions on how you might like to use these scales:

1. Don't forget that if you are somewhere between 30% and 40% (for example), you can rate yourself as somewhere between the two – 35%.
2. You can make charting your progress as simple or as complicated as you like. A simple way to use the scales would be to just write down your scores on each of the three scales along with the date and to keep rating yourself on the scales again every few months. If you'd like a more detailed account you could also:
 - Rate yourself separately for good days and bad days. (For example, one might write: 'On a good day my physical abilities are at 50%, on a bad day I'm at 30%.')
 - Few people will find that this or any other chart describes their exact combination of symptoms or experience of the illness perfectly, so you might also like to either modify the chart so that it more fully describes your own symptoms. An easier way to do this might also be to just write a few short notes about how you fit in each category (For example, one might write: 'I scored 20% on the cognitive ability scale, but my ability to handle sensory input is at about 10%.')

Terminology used in the scales

Resting: Resting means completely different things at different severity levels of illness. For the mildly ill resting may mean watching TV or perhaps sitting in a chair reading a book or having a quiet night in with friends. For the severely ill, these activities are not at all restful and indeed would provoke severe relapses.

For the very severely ill, resting means lying down in a dark room, in silence and with no sensory input at all (such as TV or radio or light) and not moving at all physically or engaging in any type of cognitive activity. Clothing must also be comfortable and the room must be neither too warm nor too cold. For the very severely ill a better term would be 'complete incapacitation,' rather than 'resting.' The term 'resting' implies that the inactivity is optional and this is often not the case in the severely ill who are often 'resting' (i.e. incapacitated) because it is physically impossible for them to do anything else.

For moderately ill patients resting means something somewhere between the two extremes, and so on.

Of course for the very severely ill there will be no safe or symptom-free activity limit. Concepts of pacing or of keeping activity at a level which does not cause immediate or delayed symptoms are useless. Indeed, a sizeable proportion of the very severely ill may well be so severely affected in the first place BECAUSE of overexertion in the early stages of their illness, because they were not told how important it was to rest or were not allowed to rest adequately. This is extremely common in M.E. It is a tragedy and an absolute disgrace.

Note that I have never heard of anyone with M.E. who is *too* restrictive with their activity levels; the problem is always the opposite, if anything. It is human nature to want to do things and to want to live and experience life as

much as possible. It is very difficult for the person with M.E. to be unable to do so many things and it requires enormous discipline to avoid overexertion. Severe M.E. restricts life to a degree that healthy people might find hard to imagine, but patients have learnt from bitter experience many times over the extreme negative consequences of overexertion. Patients are reminded of this every week if not every day as even with careful control, limits can be misjudged or tasks can take a greater toll than expected.

For most if not all patients it is much harder to rest adequately than it is to keep pushing yourself to do things even to the point of worsening the illness. It is often much easier to just keep doing things and suffer the dire consequences in the short- and long-term, rather than stand up to extreme pressure from friends, family and medical staff for these activities to be completed as they were before the patient's illness, unfortunately.

This is not about patients being as inactive as possible. Of course a person with moderate M.E. of course does not need to live with the same restrictions as does someone with severe M.E. The point here is just that patients must stay within their individual post-illness limits. No more and no less than that is necessary.

Increasing the activity levels of someone with M.E. beyond their individual limits can only ever be harmful. It really doesn't matter if this is done gradually or all at once.

Overexertion: What characterises M.E. every bit as much as the individual symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on.

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.

Sensory input: includes light, noise, movement, motion, vibration, odours, touch.

Cognitive abilities: when rating cognitive abilities it is the persons intellectual capabilities which are being referred to, not their state of mental or emotional health which will most often be at quite a different level altogether.

Symptom severity: on a scale of one to ten means:

Mild symptoms = 1/10 - 3/10. Symptoms present but at so low a level you can just about forget they are there most of the time.

Mild/moderate symptoms = 4/10 - 5/10

Moderate symptoms = 6/10 - 7/10

Severe symptoms = 8/10

Very severe symptoms = 9/10

Extremely severe symptoms = 10/10. As far as you are concerned; being eaten alive by a tiger could NOT hurt any more, or feel any worse than this does, nothing could. Absolute agony.

The pain and suffering of M.E. have a number of different ‘flavours.’ The experience can be made up of severe nausea, vertigo and disequilibrium, cold and hot fevers or feeling both very cold and very hot at the same time, feeling ‘poisoned’ and very ill, pain in the glands and throat, muscle pain, twitching and uncontrollable spasms, difficulty breathing and breathlessness, cardiac pain and pressure and dysfunction that feels like a heart attack, a feeling of having a heart attack in every organ (caused by lack of blood flow to these organs), sensations of pain and terrible pressure in the brain and behind the eyes, stroke-like or coma-like episodes, abdominal pain and pain/discomfort following meals, seizures and ‘sensory storms’ (while conscious) and, lastly, an inability to remain conscious for more than a few minutes, or hours at a time or for more than a few hours each day in total. Any one of these problems can cause severe suffering. What makes severe M.E. so terrible is that the patient is almost always dealing with a large number of these horrific problems *all at once*.

For more (fully referenced) information on M.E., see: [What is M.E.?](#) plus [Why patients with severe M.E. are housebound and bedbound](#) and [The importance of avoiding overexertion in Myalgic Encephalomyelitis](#).

See also: [M.E. vs MS: Similarities and differences](#)

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

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

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

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- 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.