

To...

My name is...

I have an illness called Myalgic Encephalomyelitis, or M.E.

The name M.E. was coined in 1956. M.E. was formally classified as an organic disease of the central nervous system (ie. a neurological disorder) in the World Health Organisation's International Classification of Diseases in 1969 with the code G.93.3. M.E. is still classified with this same code today. M.E. is an infectious neurological disease that can be clearly defined. M.E. can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934. M.E. is similar in a number of significant ways to multiple sclerosis, Lupus and poliomyelitis (polio). A large number of different abnormalities are known to occur in M.E. and the presence of the illness can be confirmed with appropriate testing (and physical exam). If the illness cannot be confirmed by testing (using PET, SPECT and MRI scans of the brain etc.), if all tests are normal (including those tests specific to M.E.), then it cannot be M.E.

This is not simply theory; the recorded medical history of M.E. as a debilitating organic neurological disease affecting both children and adults is substantial. It spans over 70 years and has been published in prestigious peer-reviewed journals all over the world.

I have had M.E. for ___ years, and my activity level is currently: _____
(See the scale overleaf for a brief description of the different ability/disability levels seen in M.E.)

The interventions known as **graded exercise therapy** (GET) and **cognitive behavioural therapy** (CBT) have been repeatedly demonstrated in the literature to be not only ineffective but specifically harmful for people with M.E. A number of deaths have even been caused by the administration of GET in people with M.E. Some more information on what the disease M.E. is:

Myalgic encephalomyelitis is a systemic acutely acquired illness initiated by a virus infection which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name Myalgic Encephalomyelitis.)

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

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) by the chronic effects of a viral infection. There is also transient and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically. Even minor levels of physical and cognitive activity, sensory input and orthostatic stress beyond a M.E. patient's individual post-illness limits causes a worsening of the severity of the illness (and of symptoms) which can persist for days, weeks or months or longer. In addition to the risk of relapse, repeated or severe overexertion can also cause permanent damage (eg. to the heart), disease progression and/or death in M.E.

This exercise intolerance is one of the unique features of M.E. – all M.E. patients worsen with even trivial levels of activity or exercise (or cognitive exertion or orthostatic stress). People with M.E. do not improve with exercise. They cannot; exercise intolerance is a large and essential part of *what M.E. is*. If a person improves with exercise they do not have M.E. Dr Melvin Ramsay, an acknowledged M.E. expert with 30 years experience in treating M.E. explains that, '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 have the best prognosis.'

The way the bodies of people with M.E. react to exercise is abnormal in a number of different ways. Strong evidence exists to show that exercise can have extremely harmful effects on M.E. patients; permanent damage may be caused, as well as disease progression: recent research has shown that postural stress (as well as activity/exercise) exacerbates the well-documented cardiac insufficiency in this disease. Patient accounts of leaving exercise programs much more severely ill than when they began them; wheelchair-bound or bed-bound or needing intensive care or cardiac care units, are common. The damage caused is often very severe

and may be either long-term or permanent. Thus some patients are still dealing with the severe physical effects of inappropriate advice to exercise (or formal GET programs) 5, 10, 15 or more YEARS afterward. These abnormal responses to exercise are so pronounced that exercise tests are actually one of the series of tests which can be used to confirm a suspected M.E. diagnosis. For example, Dr. Paul Cheney explains that when disabled M.E. patients stand up, they are 'on the edge of organ failure due to extremely low cardiac output as their Q drops to 3.7 litres per minute' (a 50% drop from the normal of 7 litres per minute).

In addition to the risk of relapse, sudden deaths have also been reported in a small percentage of M.E. patients following exercise. As M.E. expert of 20 years experience Dr. Elizabeth Dowsett, explains; '20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.' Dr Byron Hyde who also has 20 years experience in treating and studying M.E., explains that: 'I have some M.E. patients with a circulating red blood cell volume less than 50% of expected and a very large number with the range of 60% to 70%. What this test means is that blood is pooling somewhere in the body and that this blood is not available for the brain. When blood flow to the heart decreases sufficiently, the organism has an increased risk of death.'

CBT however seems at first to be the softer option of the two interventions, but CBT can also have significant negative effects both physically and psychologically. CBT to convince someone with M.E., that he/she does not have a physical disorder is disrespectful, inappropriate and cruel. It places an additional (and bogus) psychological burden on a person already suffering with severe physical illness, and can cause significant psychological harm (as well as additional severe physical relapse in the more severely affected).

There is in fact *no evidence whatsoever* which exists to show that Myalgic Encephalomyelitis can be caused or perpetuated by psychiatric or behavioural problems; nor that therapies such as CBT or GET are appropriate, safe or useful in treating M.E. patients. The studies which support these theories and the use of these therapies have been conducted not on people with M.E. but instead on patients with an entirely unrelated health problem – the symptom of fatigue.

The symptom of chronic fatigue and the distinct neurological illness M.E. each have a very different; cause, symptoms, aetiology, pathology (tests results), response to treatment, long and short term prognosis – and World Health Organization classification. Clearly it is a stretch of credibility to say that people with the symptom of chronic fatigue and those with M.E. share any real similarities – let alone that they could somehow represent the exact same patient group and be able to be studied interchangeably. M.E. is neither a psychological, behavioural or biopsychosocial disorder, nor is it 'medically unexplained' or a problem of mere 'fatigue' any more than is multiple sclerosis or Lupus.

While there may or may not be some benefit from these interventions in patients suffering the symptom of 'fatigue' CBT and GET are at best useless and at worst extremely harmful for neurological M.E. patients. (An entirely unrelated patient group.) The scientific evidence is very clear on this matter. It is unscientific and unethical that any patient with M.E. be recommended (or forced to participate in) such inappropriate programs.

M.E. is in no way 'medically unexplained.' M.E. is also not at all the same thing as 'CFS.' 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* .In short:

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

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

This letter informs you of my current physical state and warns you that my representatives will sue you for any harm caused by your use of GET and/or CBT. Deliberate ignorance of the published facts will multiply the legal cost.

For more information about M.E. including the lack of scientific legitimacy – and the hidden financial and political motivations – underlying the 'behavioural' paradigm of M.E., and most importantly the creation of the bogus disease category of 'CFS,' see the papers: Who benefits from 'CFS' and 'ME/CFS'?, Smoke and Mirrors, What is M.E.? and The effects of CBT and GET on patients with M.E. M.E. and 'CFS' are NOT the same. These papers also contain a detailed list of references for all of the medical information and other facts contained in this letter. See also Testing for Myalgic Encephalomyelitis for more information about the tests which can be useful in diagnosing M.E., and why M.E. is a distinct disease entity, and not merely 'fatigue' or a 'chronic fatigue syndrome.'

These papers are freely available to be viewed on www.hfme.org This website, among others, also contains details of hundreds more research papers, books and articles created by the world's leading M.E. experts.

Thank you for your time.
Sincerely,

Date: / /

The HFME ability scale for Myalgic Encephalomyelitis

- ❑ **MILD/MODERATELY AFFECTED** Physical activity is at around 50 - 60% 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. Cognitive functioning is at around 50 - 60% of expected. Unable to perform tasks which are excessively demanding on a cognitive level, but can complete lighter activities for 5 – 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. 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.
- ❑ **MODERATELY AFFECTED** Physical activity is at around 40 - 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/SEVERELY AFFECTED** Overall activity level reduced to around 20 - 30% of expected. Not confined to the house but may be unable to walk without support much beyond 50 to 200m, a wheelchair may be able to be used to travel longer distances. Several hours of deskwork may be possible each day if requirements for quiet and resting are met. 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. Physically undemanding social activities are possible.
- ❑ **SEVERELY AFFECTED** Overall physical activity level reduced to around 5-10% 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). Bedbound or couch-bound for 21+ hours a day. Activity is mostly restricted to managing the tasks of daily living and some assistance with or modification of tasks is often required.
- ❑ **VERY SEVERELY AFFECTED** 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.
- ❑ **EXTREMELY SEVERELY AFFECTED** 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.
- ❑ **PROFOUNDLY SEVERELY AFFECTED** Completely bedbound and often/always unable to turn or move in bed (or at all) unassisted. Eating is extremely difficult and liquid food may be necessary. Swallowing liquids may also be difficult/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 and lasting relapses in symptoms and so only be able to be attempted occasionally. 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 extremely difficult or impossible. There is very severe (9/10) pain and/or overwhelming sensations of illness/dysfunction throughout the body and brain *continually* - 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 a few seconds or a minute at a time.

This is a summarised version of the full-length 'M.E. Ability Scale' available on www.hfme.org

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

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



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

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Taken from www.hfme.org

- 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.