

## 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 million stories untold

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‘Imagine if your entire well-being depended on the telling of a story’ (Munson, P. 2000, p. xxiii).

Imagine having to tell that story not just once but over and over again, all the while experiencing unspeakable pain, horrific symptoms of illness, and cognitive confusion so profound that you struggle to remember how to speak at all. Imagine that story, the story of your life, not being believed time and time again despite there being an enormous amount of *irrefutable* scientific evidence spanning over 70 years that backs up exactly what you are saying.

This is the position more than a million adults, teenagers and children find themselves in because they are unlucky enough, through no fault of their own, to have the ‘wrong’ disease. A disease with so much misinformation and propaganda attached to it that this often causes almost as much pain and suffering as the illness itself.

I’d like to attempt to tell at least some of their real story, the story based in fact rather than fiction. It’s a somewhat complicated tale but one that needs telling and needs desperately to become public knowledge. I’m begging you, just for the few minutes it will take to read this, please let go of what you already ‘know’ about this illness.

First of all, the illness I’m talking about is called Myalgic Encephalomyelitis or M.E. That is the correct name for this illness, and it has been since 1956. In 1988 in the US, the fictional disease category of ‘Chronic Fatigue Syndrome’ (CFS) was created – but despite popular opinion, M.E. and ‘CFS’ are *not* synonymous terms and M.E. and ‘CFS’ are not the same thing. M.E. has nothing to do with ‘tiredness’ and is not medically unexplained. I’ll explain how these two very different entities are falsely linked a bit later on.

(Okay, now remember what I said about forgetting the rumours you may have heard – because they ARE rumours. They aren’t based on facts. Yet again it is a shocking case of mere financial gain being put before ethics or science).

I have been unlucky enough to have had M.E. for the past 15 years, since I was just 19. I went from being perfectly healthy and active to being severely disabled from one day to the next. I’m 100% housebound and 99.5% bedbound, yet like so many other M.E. sufferers I have had to fight so hard just to try to get even basic help and understanding from doctors, friends and family members.

So little is known by the public about this illness. This is hardly surprising when it’s common for journalists to produce articles on this illness that do not contain even a *single* fact! Few people are aware that M.E. not only affects people individually, but that there have been many documented *outbreaks* of the illness. Most people also have no idea of the brutal severity of M.E., or the deaths from M.E., or that M.E. affects children as young as 5 as well as adults, or the wide array of serious and disabling symptoms that are associated with M.E. or that people with M.E. would give *anything* to instead be merely very ‘fatigued’ or ‘tired all the time.’

#### So what IS Myalgic Encephalomyelitis?

Myalgic encephalomyelitis is an 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.) M.E. also causes a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits.

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected. 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. Thus M.E. symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular,

immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

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

It is the combination of the chronicity, the dysfunctions, and the instability, the lack of dependability of these functions, that creates the high level of disability in M.E. It is also worth noting that of the CNS dysfunctions, cognitive dysfunction is one of the most disabling characteristics of M.E. All of this is not simply theory, but is based upon an enormous body of mutually supportive clinical information. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on (Chabursky et al. 1992 p. 20) (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 pp. x-xxi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92).

- See [What is M.E.?](#) and [M.E. -The Medical Facts](#) for more medical information about M.E.
- *What is [Homeostasis](#)?* Homeostasis is the property of a living organism, to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits.

### **What are the real physical effects of Myalgic Encephalomyelitis?**

M.E. is similar in a number of significant ways to [multiple sclerosis](#), Lupus and poliomyelitis (polio). M.E. can be extremely severe and disabling and in some cases the disease is fatal.

M.E. can leave you unable to read even a few lines of text, write, watch TV, or have the radio on. You can be unable to speak, or to understand speech in any way.... and this really is every bit as terrifying as you can imagine. Your throat, glands and muscles can all hurt beyond the reach of medication as you go in and out of fevers, unable to sit up for more than a few minutes, or even a few seconds. Your heart can beat erratically or very fast, sometimes for hours and it can feel like you are having a heart attack. Standing up for any length of time can make you feel like you are dying or like you are having a heart attack in EVERY organ. You can have real difficulty breathing or breathing can stop altogether. The smallest amount of noise, light or vibration can be agony and cause seizures.

You can have stroke-like episodes. The room can spin with constant vertigo and you can become allergic or sensitive to so many drugs (including vitamins and supplements), chemicals and foods. You can have seizures or experience episodes of paralysis. You can lie awake with insomnia all night, desperately in need of sleep but unable to get to sleep for many hours, or for more than a few hours at a time because you can't get into the proper deep stages of sleep anymore and every small noise wakes you. You can also suffer with sleep paralysis. Worst of all, you very often have to deal with a long list of these symptoms all at the same time, just constantly, with no respite.

Symptoms of M.E. include (in no particular order):

Sore throat, chills, sweats, low body temperature, low grade fever, lymphadenopathy, muscle weakness (or paralysis), muscle pain, muscle twitches or spasms, gelling of the joints, hypoglycaemia, hair loss, nausea, vomiting, vertigo, chest pain, cardiac arrhythmia, resting tachycardia, orthostatic tachycardia, orthostatic fainting or faintness, circulatory problems, ophthalmoplegia, eye pain, photophobia, blurred vision, wavy visual field, and other visual and neurological disturbances, hyperacusis, tinnitus, alcohol intolerance, gastrointestinal and digestive disturbances, allergies and sensitivities to many previously well-tolerated foods, drug sensitivities, stroke-like episodes, nystagmus, difficulty swallowing, weight changes, paresthesias, polyneuropathy, proprioception difficulties, myoclonus, temporal lobe and other types of seizures, an inability to maintain consciousness for more than short periods at a time, confusion, disorientation, spatial disorientation, disequilibrium, breathing difficulties, emotional lability, sleep disorders; sleep paralysis, fragmented sleep, difficulty initiating sleep, lack of deep-stage sleep and/or a disrupted circadian rhythm.

Neurocognitive dysfunction may include cognitive, motor and perceptual disturbances. Cognitive dysfunction may be pronounced and may include; difficulty or an inability to speak (or understand speech), difficulty or an

inability to read or write or to do basic mathematics, difficulty with simultaneous processing, poor concentration, difficulty with sequencing and problems with memory including; difficulty making new memories, difficulty recalling formed memories and difficulties with visual and verbal recall (eg. facial agnosia). There is often a marked loss in verbal and performance intelligence quotient (IQ) (Bassett 2010, [Online]).

There are also many more symptoms that occur commonly in M.E. but I'm trying to be as brief as I can. More than 64 distinct symptoms have been authentically documented in M.E.

But 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 (being upright), and so on. The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain (the central nervous system) this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made.

The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) in Myalgic Encephalomyelitis include:

- A. People with M.E. are unable to maintain their pre-illness activity levels. This is an acute (sudden) change. M.E. patients can only achieve 50%, or less, of their pre-illness activity levels post-M.E.
- B. People with M.E. are limited in how physically active they can be but they are also limited in similar way with; cognitive exertion, sensory input and orthostatic stress.
- C. When a person with M.E. is active beyond their individual (physical, cognitive, sensory or orthostatic) limits this causes a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.
- D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress needed to cause a significant or severe worsening of symptoms varies from patient to patient, but is often trivial compared to a patient's pre-illness tolerances and abilities.
- E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.
- F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours (or more) later.
- G. The effects of overexertion can accumulate over longer periods of time and lead to disease progression, or death.
- H. The activity limits of M.E. are not short term: a gradual (or sudden) increase in activity levels beyond a patient's individual limits can only cause relapse, disease progression or death in patients with M.E.
- I. The symptoms of M.E. do not resolve with rest. The symptoms and disability of M.E. are not just caused by overexertion; there is also a base level of illness which can be quite severe even at rest.
- J. Repeated overexertion can harm the patient's chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
- K. Not every M.E. sufferer has 'safe' activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected (Bassett 2009, [Online]).

As you can see not only does M.E. affect what seems like just about everything physically but there are extensive neurological and cognitive and sensory problems (and injuries) as well. With M.E. you can be unable to speak or to recognise the face of your sibling sitting right in front of you and struggle to breathe or to sit up all at the same time. Nothing is left except your mind, your personality...

Not only can't you do almost anything anymore, but it can even make you very ill for people to do things for you, or even around you – almost every sort of movement or stimulus can make you severely more ill. (For example, not only do many severe M.E. sufferers become unable to speak, many also cannot tolerate hearing the speech of others, so lack of communication is a real problem. M.E. causes an intense level of isolation. Some sufferers must resort to using hand signals to communicate. One of the worst parts of having M.E. is that so often we can have no DISTRACTION from the symptoms as those with so many other illnesses can, or much basic communication with others even. M.E. is an intensely private and isolating agony.) This illness can take away EVERYTHING. The payback from doing even the smallest tasks can be extremely severe and can last for weeks, months or even years. Severe M.E. can mean being left in a dark quiet room in agonising pain, barely able or unable to think or move, or read or write, or to speak or be spoken to – for months, years or decades.

Forget just trying to get through one day at a time as some days you have to take each hour, or minute, or even SECOND as it comes – and each second can sometimes last for what feels like hours. It's hell on earth. M.E. is one of the most disabling illnesses there is.

- For a more complete (and fully referenced) M.E. symptom list see: [The ultra-comprehensive M.E. symptom list](#)

- To read a description of the symptoms of M.E. which combines the available research with a *personal* description of the illness, and which describes more than 50 symptoms of the illness in detail, see my new paper: [What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E.](#)

### **What else defines Myalgic Encephalomyelitis?**

M.E. can be very unpredictable – symptoms can constantly change from each week, day and hour to the next. I'll finally find a treatment or a way to work around a symptom I've had for months when it will gradually disappear of its own accord only to be replaced by something completely different but equally disabling. It's so frustrating.

The severity of symptoms is also extremely variable. Maybe for an hour or two once a week or so I'll be able to maybe have a friend come for a quiet visit, or maybe paint, but these magical hours (or half hours more likely) are by no means assured and there have been times where months have gone by without one. There are also a large number of problems, cognitive as well as physical, that are constant, so I am never symptom-free or able to do such tasks without extensive modifications and careful planning beforehand. I also often pay the price for such activities by feeling much sicker 48 or so hours afterward, for hours or days. Usually days. But sometimes weeks or months.

Some days are better than others but then suddenly you can become extremely ill from one hour to the next without warning (which makes it almost impossible to plan anything ahead of time). I am never sure what sort of problems I'll have to deal with when I wake up each morning - all I know is that they'll be serious, especially if I've done anything other than rest in the days and weeks and months before. Worse than 'usual' days also happen for no reason at all. This waxing and waning pattern of symptoms/severity is diagnostic of the illness.

The payback you get from certain tasks is often out of all proportion in M.E. too, for example I have spent 6 months recovering from a week in hospital, and an entire week very severely ill recovering from a mere half-hour phone call. M.E. doesn't care at all about what is reasonable! The worsening of the illness caused by even minor tasks can just so often be ridiculously severe and last for what seems like a ridiculously long time. If you do too much in the long term it can even lead to disease progression or death. You can't get away with anything when you have M.E., every small activity has a price post-illness.

Strong evidence exists to show that overexertion can have extremely harmful effects on M.E. patients. 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. (Recent research has shown that postural stress and physical and mental overexertion exacerbate cardiac insufficiency in this disease; see the notes below for more information.) In addition to the risk of relapse, permanent damage, and disease progression, there have also been reports of sudden deaths in M.E. patients following exercise. As M.E. expert [Dr. Elizabeth Dowsett](#) explains, '20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise. Prompt recognition and advice to avoid over-exertion is mandatory.'

It is sometimes claimed that while exercise programs are not safe or appropriate for the severely affected, that mild or moderately affected M.E. sufferers can benefit from such interventions. But this assertion is NOT supported by the evidence. (Some miscellaneous 'fatigue' sufferers have been shown to benefit from graded exercise programs, but the results of these studies are no more relevant to mild M.E. sufferers than they are to severe M.E. sufferers; people with 'fatigue' do NOT have mild M.E. any more than they have mild multiple sclerosis, mild Lyme disease, mild cancer or any other illness.) Recent studies have shown that graded exercise programs are the actual reason many with M.E. are so severely affected in the first place, thus exercise programs should not be considered safe for M.E. sufferers of any severity. Graded exercise *cannot* improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E.

Encouraging your friend or family member to exercise themselves well, (or to 'positive think' themselves well), is just really cruel and unfair. No matter how hard they try, it can NEVER work – but it can leave them permanently more disabled unfortunately (and trust me you don't want to have to live with having contributed to doing that to another person... that is an immense amount of guilt to have to carry). Studies showing improvement with exercise and cognitive behavioural therapy have NOT been conducted on M.E. patients but instead psychological 'fatigue' sufferers – an entirely different and UNRELATED patient group, and of course you simply cannot determine treatments for one group by looking at entirely different one! No matter how long you study people with Alzheimers you wont come up with a cure for diabetes, and no matter how long you study tired people, you wont come up with a cure for Myalgic Encephalomyelitis, and so on.

Like so many people with M.E., the reason I am severely affected *is because* I was given advice to exercise for the first 5 years I was ill. When I was first ill I could still do around 40-50% of my pre-illness activities. Thanks to

this bad medical advice, I have only been able to do far less than even 5% of my pre-illness activities for the last 7 years now. That bad advice I was given to exercise...I don't think it's an exaggeration to say it has ruined my life, and that it will negatively affect my health for the rest of my life too. Please don't let this happen to your friend or family member with M.E.! It is such a waste, and what is done can never be undone...

**So *why* is Myalgic Encephalomyelitis not regarded as a serious illness by some people? Why do some groups claim it is merely a problem of 'fatigue' or a psychological or behavioural illness?**

Why is so little money going into M.E. research? Why is it so difficult to get social security payments when you are so severely ill? Why are so many friends and families of sufferers not only not supportive, but downright dismissive of them or even abusive? Why do so many people with M.E. suffer abuse and neglect at the hands of their doctors, nurses and carers? Why are parents being unfairly blamed for their children's illness? Why are the more than a thousand studies proving the existence of serious abnormalities in M.E. not enough? Why is so little being done to change all these things?

It all comes down to money, unfortunately. Money and politics, and the creation of the disease category of 'Chronic Fatigue Syndrome.' The disease category of CFS was created in 1988 in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not exist.

There was an enormous rise in the reported incidence of Myalgic Encephalomyelitis in the late 1970s and the 1980s and so it was at this time that certain psychiatrists and others involved in the medical insurance industry (on both sides of the Atlantic) began their campaign to reclassify the severely incapacitating and discrete neurological disorder known as Myalgic Encephalomyelitis as a psychological or 'personality' disorder; in order to side-step the financial responsibility of so many new claims (Marshall & Williams 2005a, [Online]). As Professor Malcolm Hooper explains:

In the 1980s in the US (where there is no NHS and most of the costs of health care are borne by insurance companies), the incidence of ME escalated rapidly, so a political decision was taken to rename M.E. as "chronic fatigue syndrome", the cardinal feature of which was to be chronic or on going "fatigue", a symptom so universal that any insurance claim based on "tiredness" could be expediently denied. The new case definition bore little relation to M.E.: objections were raised by experienced international clinicians and medical scientists, but all objections were ignored... To the serious disadvantage of patients, these psychiatrists have propagated untruths and falsehoods about the disorder to the medical, legal, insurance and media communities, as well as to government Ministers and to Members of Parliament, resulting in the withdrawal and erosion of both social and financial support [for M.E. patients]. Influenced by these psychiatrists, government bodies around the world have continued to propagate the same falsehoods with the result that patients are left without any hope of understanding or of health service provision or delivery. As a consequence, government funding into the biomedical aspects of the disorder is non-existent. (2003a, [Online]) (2001, [Online])

That's it, in a nutshell. The creation of 'CFS' – and the claims that the distinct neurological illness M.E. and 'CFS' are the same thing – is just an insurance scam, designed to save certain large corporations literally millions or even billions of dollars. It has been remarkably successful unfortunately, to the detriment of more than a million severely disabled patients left without financial support, medical care, or even support or kindness from their closest friends and family in many cases.

To be blunt, many people with M.E. are simply left at home alone, to die. All because political and financial considerations have been placed above ethics and basic human rights, and REALITY. Unfair doesn't even begin to describe it... The public has been misled and just plain *lied to* about the reality of M.E. by various vested interest groups, by mainstream media and by government for the last 20 years, and this looks set to continue for another 20 years the way things are going... It is a scientific fraud and a human rights travesty on a massive scale. (See: Who benefits from 'CFS' and 'ME/CFS'?)

**Setting the record straight - the truth about Myalgic Encephalomyelitis**

Is Myalgic Encephalomyelitis a new illness? What does the name M.E. mean?

M.E. is thought to have existed for centuries. (Hyde 1998, [Online]) (Dowsett 1999a, [Online]). One of the most fundamental facts about M.E. throughout its history is that it occurs in epidemics. There is a history of over sixty recorded outbreaks of the illness going back to 1934 when an epidemic of what seemed at first to be poliomyelitis was reported in Los Angeles. As with many of the other M.E. outbreaks the Los Angeles outbreak occurred during a local polio epidemic.

A review of early M.E. outbreaks found that clinical symptoms were consistent in over sixty recorded epidemics spread all over the world (Hyde 1998, [Online]). Despite the different names being used, these were repeated

outbreaks of the same illness. It was also confirmed that the epidemic cases of M.E., and the sporadic cases of M.E. each represented the same illness (Hyde 2006, [Online]) (Dowsett 1999a, [Online]).

In 1956 the name Myalgic Encephalomyelitis was created. The term Myalgic Encephalomyelitis means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation (Hyde 2006, [Online]). In recognition of the large body of compelling research that was available, M.E. was formally classified as an organic disease of the central nervous system in the World Health Organisation's International Classification of Diseases in 1969 (Hooper et al. 2001, [Online]). This classification remains unchanged today.

### What causes Myalgic Encephalomyelitis?

M.E. expert Dr Byron Hyde explains that:

[The] prodromal phase is associated with a short onset or triggering illness. This onset illness usually takes the form of either, or any combination, of the following, (a) an upper respiratory illness, (b) a gastrointestinal upset, (c) vertigo and (d) a moderate to severe meningitic type headache. The usual incubation period of the triggering illness is 4-7 days. The second and third phases of the illness are usually always different in nature from the onset illness and usually become apparent within 1-4 weeks after the onset of the infectious triggering illness (1998 [Online]).

Despite popular opinion (and the vast amount of government and media propaganda) there is **no** link however between contracting M.E. and being a 'perfectionist' or having a 'type A' or over-achiever personality. M.E. also **cannot** be caused by a period of long-term or intense stress, trauma or abuse in childhood, becoming run-down, working too hard or not eating healthily. Myalgic Encephalomyelitis is not a form of 'burnout' or nervous exhaustion, or the natural result of a body no longer able to cope with long-term stress.

Research also shows that it is simply not possible that M.E. could be caused by the Epstein-Barr virus, any of the herpes viruses (including HHV6), glandular fever/mononucleosis, Cytomegalovirus (CMV), Ross River virus, Q fever, hepatitis, chicken pox, influenza or any of the bacteria which can result in Lyme disease (or other tick-borne bacterial infections). M.E. is also not a form of chemical poisoning.

M.E. is undoubtedly caused by a virus, a virus with an incubation period of 4-7 days. The evidence indicates that the culprit is an enterovirus; the same type of virus which causes polio (Hyde 2006, [Online]) (Hyde 2007, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003a, [Online]) (Dowsett 2001a, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Ryll 1994, [Online]).

### What does a diagnosis of 'CFS' actually mean?

There are now more than nine different definitions of 'CFS.' All each of these flawed CFS definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue. The fact that a person qualifies for a diagnosis of CFS, based on any of the CFS definitions (a) does not mean that the patient has Myalgic Encephalomyelitis, and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.'

A diagnosis of CFS – based on any of the CFS definitions – can only ever be a *misdiagnosis*. All a diagnosis of 'CFS' actually means is that the patient has a gradual onset fatigue syndrome which is usually due to a *missed major disease*. As M.E. expert Dr Byron Hyde explains, the patient has:

a. Missed cardiac disease, b. Missed malignancy, c. Missed vascular disease, d. Missed brain lesion either of a vascular or space occupying lesion, e. Missed test positive rheumatologic disease, f. Missed test negative rheumatologic disease, g. Missed endocrine disease, h. Missed physiological disease, i. Missed genetic disease, j. Missed chronic infectious disease, k. Missed pharmacological or immunization induced disease, l. Missed social disease, m. Missed drug use disease or habituation, n. Missed dietary dysfunction diseases, o. Missed psychiatric disease (2006, [Online]).

Under the cover of 'CFS' certain vested interest groups have assiduously attempted to obliterate recorded medical history of Myalgic Encephalomyelitis; even though the existing evidence has been published in prestigious peer-reviewed journals around the world and spans over 70 years. As Dr Byron Hyde explains:

Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis. It is not. The CDC 1988 definition of CFS describes a non-existing chimera based upon inexperienced individuals who lack any historical knowledge of this disease process. The CDC definition is not a disease process. Any disease process that has major criteria, of excluding all other disease processes, is simply not a disease at all; it doesn't exist. The CFS definitions were written in such a manner that CFS becomes like a desert mirage: The closer you approach, the faster it disappears (2006, [Online]).

The only way forward for M.E. patients and all of the diverse patient groups commonly misdiagnosed with 'CFS' (both of which are denied appropriate support, diagnosis and treatment, and may also be subject to serious medical abuse) is that the bogus disease category of 'CFS' must be abandoned. Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery and this process must begin with a correct diagnosis if at all possible. *A correct diagnosis is half the battle won* (Hyde 2006a, 2006b, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online]) (Hooper 2003a, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett n.d., [Online]).

- For more information on why the bogus disease category of 'CFS' must be abandoned, (along with the use of other vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'CFIDS' and 'Myalgic Encephalopathy' and others), see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename 'CFS' as 'ME/CFS' and Problems with the use of 'ME/CFS' by M.E. advocates](#), plus [The misdiagnosis of CFS, Why the disease category of 'CFS' must be abandoned and Smoke and Mirrors](#)
- *An additional note on 'fatigue'*: Just as some M.E. sufferers will experience other minor and non-essential symptoms such as vomiting or night sweats some of the time, but others will not, the same is true of fatigue. The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms (and so on) – the presence or absence of mere 'fatigue' is irrelevant. M.E. is defined by measurable damage to the CNS, not mere 'fatigue.'

#### Myalgic Encephalomyelitis is not defined by mere 'fatigue'

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

M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of mere 'chronic fatigue' – if only! (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d., [Online]).

- For more information see [Myalgic Encephalomyelitis is not fatigue, or 'CFS'](#).

#### What do the terms CFIDS, ME/CFS, CFS/ME, Myalgic Encephalopathy and ME-CFS mean?

When the terms CFS, CFIDS, ME/CFS, CFS/ME, Myalgic Encephalopathy or ME-CFS are used what is being referred to may be patients with/facts relating to any combination of: 1. Miscellaneous psychological and non-psychological fatigue states (including somatisation disorder) 2. A self limiting post-viral fatigue state or syndrome (eg. following glandular fever.) 3. A mixed bag of unrelated, misdiagnosed illnesses (each of which feature fatigue as well as a number of other common symptoms; poor sleep, headaches, muscle pain etc.) including Lyme disease, multiple sclerosis, Fibromyalgia, athletes over-training syndrome, depression, burnout, systemic fungal infections (candida) and even various cancers 4. Myalgic Encephalomyelitis patients.

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.

The only thing that makes any sense is for patients with Myalgic Encephalomyelitis, to be studied ONLY under the name Myalgic Encephalomyelitis – and for this term ONLY to be used to refer to a 100% M.E. patient group. The only correct name for this illness – M.E. as per Ramsay/Richardson/Dowsett and Hyde – is Myalgic Encephalomyelitis. M.E. is not synonymous with CFS, nor is it a subgroup of CFS. (There is no such disease/s as 'CFS'.)

#### Is Myalgic Encephalomyelitis difficult to diagnose? What tests can be used to diagnose M.E.?

M.E. is a distinct, recognisable disease entity that is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease (within just a few weeks) – providing that the physician has some experience with the illness.

Although there is as yet no single test which can be used to diagnose M.E. there are (as with Lupus and multiple sclerosis and ovarian cancer and many other illnesses) a *series* of tests which can confirm a suspected M.E. diagnosis. Virtually every M.E. patient will also have various abnormalities visible on physical exam. (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hooper et al. 2001, [Online]) (Chabursky et al. 1992, p.22). As Dr Byron Hyde explains:

The one essential characteristic of M.E. is acquired CNS dysfunction. A patient with M.E. is a patient whose primary disease is CNS change, and this is measurable. We have excellent tools for measuring these physiological and neuropsychological changes: SPECT, xenon SPECT, PET, and neuropsychological testing (2003, [Online]).

If all tests are normal then a diagnosis of M.E. cannot be correct (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett n.d., [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92).

- See: Testing for M.E. for more information on the various tests which can aid M.E. diagnosis.

#### It is only Myalgic Encephalomyelitis patients who are negatively affected by the bogus creation of 'CFS'?

Other patient groups misdiagnosed as CFS are also denied appropriate diagnosis and treatment and they may also routinely be subjected to inappropriate psychological interventions (such as CBT and GET). There are also a variety of negative impacts on doctors and the public (and others) caused by the 'CFS' insurance scam. Truly the only groups which gain from the 'CFS' confusion are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.

#### Is there a legitimate scientific debate about whether or not M.E. is a 'real' medical condition?

Despite popular opinion, there simply is no legitimate scientifically motivated debate about whether or not M.E. is a 'real' illness or not or has a biological basis. The psychological or behavioural theories of M.E. are no more scientifically viable than are the theories of a 'flat earth.' *They are pure fiction.*

#### What is known about Myalgic Encephalomyelitis so far?

There is an abundance of research which shows that M.E. is an organic illness which can have profound effects on many bodily systems. These are well-documented, scientifically sound explanations for why patients are bedridden, profoundly intellectually impaired, unable to maintain an upright posture and so on. More than a

**thousand** good articles now support the basic premises of M.E. Autopsies have also confirmed such reports of bodily damage and infection (Hooper & Williams 2005a, [Online]).

It is known that Myalgic Encephalomyelitis is: an acute onset (biphasic) epidemic or endemic infectious disease process, an autoimmune disease (with similarities to Lupus), an infectious neurological disease, affecting adults and children, a persistent viral infection (most likely due to an enterovirus; the same type of virus which causes poliomyelitis and post-polio syndrome), a central nervous system (CNS) disease (with similarities to MS), a variable (but always, serious) diffuse (acquired) brain injury, a systemic illness (associated with organ pathology; particularly cardiac), a vascular disease, a cardiovascular disease, a type of cardiac insufficiency, a mitochondrial disease, a metabolic disorder, a musculo-skeletal disorder, a neuroendocrine disease, a seizure disorder, a sleep disorder, a gastrointestinal disorder, a respiratory disorder, an allergic disorder, a pain disorder, a life-altering disease, a chronic or lifelong disease associated with a high level of disability, an unstable disease; from one hour/day/week or month to the next and potentially progressive or fatal disease (Hyde 2007, [Online]) (Hooper et al. 2001, [Online]) (Cheney 2007, [video recording]) (Ramsay 1986, [Online])

- For more information on all aspects of M.E. see: [What is Myalgic Encephalomyelitis?](#)

#### Who gets Myalgic Encephalomyelitis?

M.E. has a similar strike rate to multiple sclerosis (or possibly somewhat higher), and is estimated to affect roughly 0.2% of the population. Children and teenagers are also susceptible to the illness and children as young as five have been diagnosed with M.E. **M.E. affects all ethnic and socio-economic groups and has been diagnosed all over the world. There are more than a million M.E. sufferers worldwide** (Hooper et al. 2001 [Online]) (Hyde 1992, pp. x - xxi).

#### M.E. can be far more severe and disabling than many other illnesses

Like many others with this illness (25 – 30%), I have severe M.E. I am completely housebound and mostly bedbound. I am usually well enough to shuffle to the toilet and bathroom when I need to, I can turn myself in bed, and I can feed, dress and wash myself although these tasks are extremely difficult for me. But that's about it and these basic tasks are usually all I can do in a day. I have to rely on other people to do all the housework, cook and cut up my food for me, wash my clothes, buy things for me and make phone calls on my behalf. Pretty much everything. I am never free of many of the symptoms mentioned previously. Sometimes I am also paralysed, unable to speak, have small seizures or I have fevers that can last on and off for weeks. I am always in pain. At the moment I'm well enough to also be able to have a friend visit once every week or two for a few hours and/or to write or paint occasionally for short periods.

But there are also people who have even more severe M.E. than I do (some of them young children, tragically). One woman I know with M.E. has almost died twice from this illness. On the second occasion she stopped being able to breathe by herself, to swallow even her own saliva or to speak or tolerate hearing speech at all. She was having grand mal seizures daily despite medication. She had severe muscle twitches and hallucinated due to extreme pain. She was completely paralysed for months and had to be turned, fed, and bathed by others. Doctors gave up on her and she was sent home to die. Thankfully she was then visited by a specialist who she credits with saving her life. She says, 'It took months before I became a bit better again and could move/whisper and swallow a bit.' But she is still almost entirely bedbound and needs daily help with all her personal care.

One doctor found that: 'M.E. patients experienced greater "functional severity" than the studied patients with heart disease, virtually all types of cancer, and all other chronic illnesses.' An unrelated study compared the quality of life of people with various illnesses, including patients undergoing chemotherapy or haemodialysis, as well as those with HIV, liver transplants, coronary artery disease, and other ailments, and again found that M.E. patients scored the lowest. "In other words", said one doctor in a radio interview, "this disease is actually more debilitating than just about any other medical problem in the world" (Munson 2000, p. 4).

In the 1980s Mark Loveless, an infectious disease specialist and head of the AIDS and M.E. Clinic at Oregon Health Sciences University, found that M.E. patients whom he saw had far lower scores on the Karnofsky performance scale than his HIV patients even in the last week of their life. He testified that a M.E. patient, 'feels effectively the same every day as an AIDS patient feels two weeks before death' (Hooper & Marshall 2005a, [Online]).

Some people have 'only' moderate M.E. But people with moderate illness are still doing it really tough. Dealing with the varied symptoms of M.E. while trying to also study or work part time (often with little or no support or

understanding) leaves people struggling extremely hard just to get by, leaving nothing much left over for anything else in life. Even in moderate cases, M.E. is one of the most frightening, tragic and debilitating illnesses there is.

### The prognosis for M.E. varies, but in general M.E. is a chronic or lifelong illness

M.E. can be progressive, degenerative (change of tissue to a lower or less functioning form, as in heart failure), chronic, or relapsing and remitting. When asked on CNN how many of his M.E. patients had fully recovered in fifteen years, Dr Peterson equivocally and chillingly stated, 'None.' (Munson, P. p. 5)

Some patients experience spontaneous remissions albeit most often at a greatly reduced level of functioning compared to pre-illness and such patients remain susceptible to relapses for the remainder of their lives – M.E. is a life-long disability where relapse is always possible. Cycles of severe relapse are common, as are further symptoms developing over time. Around 30% of cases are progressive and degenerative and sometimes M.E. is fatal. As M.E. expert [Dr Elizabeth Dowsett](#) explains:

After a variable interval, a multi-system syndrome may develop, involving permanent damage to skeletal or cardiac muscle and to other "end organs" such as the liver, pancreas, endocrine glands and lymphoid tissues, signifying the further development of a lengthy chronic, mainly neurological condition with evidence of metabolic dysfunction in the brain stem. Yet, stabilisation, albeit at a low level, can still be achieved by appropriate management and support. The death rate of 10% occurs almost entirely from end-organ damage within this group (mainly from cardiac or pancreatic failure). It has to be said that suicide in younger patients and in earlier stages of the disability is related to the current climate of disbelief and rejection of welfare support... It is an additional and potentially avoidable factor (2001, [Online]).

But there is a way to ensure the most positive prognosis for people with M.E., thankfully. We know that M.E. patients who are given advice to rest in the early stages of the illness (and who avoid overexertion thereafter) have repeatedly been shown to have the most positive long-term prognosis. As Dr Melvin Ramsay explains, '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**' (1986 [Online]). The only problem is that so few people with M.E. are given the appropriate advice and support they need in order to avoid this overexertion, so many people with M.E. are far more severely ill than they need to be, unfortunately and there have also been many needless deaths from M.E. because of the lack of appropriate information and support.

- See [Treating M.E.](#) for more information on the importance of avoiding overexertion in M.E.
- *A note to those newly diagnosed with M.E.;* Never lose hope that you will be one of the lucky ones that never has the severe version of the illness and that you will experience significant recovery. You'll have a far better chance than most if you have been/are lucky enough to be able to avoid overexertion right from the start of your illness. Appropriate rest and support can also stabilise the illness at virtually any stage of severity, albeit at a low level.

### **Conclusion**

As I mentioned at the beginning, common misconceptions about M.E. mean that it affects so much more than just the health of its victims. It can negatively impact on almost every aspect of life until you are left with absolutely nothing. People often lose their jobs, their houses, their spouses and families, their friends, their financial security as well as their standing in the community and basic respect – all while dealing with severe disability and illness with none (or very little) of the appropriate support given to those with medically comparable illnesses.

It can destroy also your identity and sense of self worth – being told you are lazy, malingering or choosing to be ill over and over again takes an enormous emotional toll, especially when these accusations come from close friends and family members, or a trusted doctor. One sufferer writes: "It is difficult to describe the effect of being told you are not really ill when you are. The disjuncture between private experience and public image is so severe" (Griffin 2000, p. 32).

Patricia Fennell, a psychosocial clinician and researcher has found that many M.E. patients experience: "A post traumatic stress disorder (PTSD) -like syndrome because of the social context in which they are sick." This trauma, she asserts, "Is caused by abusive and/or ignorant doctors, a negative cultural response, and the overwhelming and continuous grief of remaining sick for a long period of time without relief" (Munson, P. 2000, p.9)

People with M.E. are also very often subjected to medical abuse and neglect. Two of the most common interventions people with M.E. are recommended to participate in are cognitive behavioural therapy (CBT) and graded exercise therapy (GET). CBT and GET are at best useless and at worst extremely harmful – or fatal – for Myalgic Encephalomyelitis patients. If a prescription drug had anything like the appalling track record exercise

has with people with M.E. (or even a small fraction of it; even 2%) it would be an enormous worldwide scandal. Despite this, people with M.E. are routinely being recommended (or FORCED to participate in) these ‘treatments’ while also being assured that they are completely safe. It is also of great concern that so many M.E. patients are ONLY offered ‘treatments’ such as CBT and GET – while access to even basic appropriate medical care is withheld. Some sufferers are also taken into psychiatric care against their will, and despite their not suffering with any mental illness. Many M.E. sufferers have no appropriate medical care at all and many with M.E. are severely ill because of this lack of care, or the lack of appropriate medical care (or financial support).

- For more information on CBT and GET see: [What is Myalgic Encephalomyelitis?](#), [The effects of CBT and GET on patients with Myalgic Encephalomyelitis](#) and [Smoke and mirrors](#).
- A recent example of a M.E. sufferer being taken into psychiatric care against their will is the case of Sophia Mirza in the UK. Tragically, Sophia died of her illness shortly after being wrongly sectioned under the Mental Health Act. Sophia was severely ill with M.E. and bedbound but she was refused even basic medical care, and this is believed to have contributed greatly to her death. For more information on this tragic case, and entirely avoidable death, see: [Inquest Implications](#), [Civilization: Another word for barbarism](#) and [The Story of Sophia and M.E.](#) For more information about forced exercise and other ‘treatments’ used on M.E. patients see the 100+ page [CBT and GET Database](#).

As if medical abuse and neglect weren’t enough to deal with, the propaganda surrounding M.E. can also lead to abuse and even ridicule from the friends and family of people with M.E. This is a very common problem facing people with M.E. (including myself, in the past). I often wonder if these friends and family members would act the same way if these people multiple sclerosis rather than M.E. With some I think not, but with others....I think some people just like to pick on those less able to defend themselves and the whole ‘CFS’ propaganda mess, and the confusion between M.E. and CFS, is just a convenient excuse. As one M.E. sufferer explains:

In spite of ample evidence to the contrary, some people will simply prefer to believe that [M.E.] and other disabilities are nothing more than depression and hysteria. In my own opinion, such people find that it serves their own purposes better to think that way. They are mere opportunists (Rotholz 2000, p. 228).

But it is the children with M.E. and their families who perhaps pay the highest price for the ignorance about this illness. Because it is harder to pin the blame for the illness on depression or anxiety with children, the parents are often blamed instead. Parents of these ill children have been charged with neglect or accused of actually making their children ill themselves. Some parents have lost custody and their children have been placed in foster care. All of this while the child continues to be seriously ill and not receive any sort of appropriate medical care. There are also other serious problems for the child:

Misdiagnosing M.E. as school phobia, depression, or separation anxiety or chalking it up to family problems places the blame squarely on the shoulders of the child. When adults experience this kind of scepticism, they usually are able to defend themselves against the mistaken ideas of others. Children are unable to do so; they depend on adults for information, explanations, sympathy and advice. To throw disbelief in the face of a child who not only has all the symptoms of M.E. but is terribly frightened and in profound need of reassurance is not only cruel, it is detrimental to the child's future emotional growth. Though school officials and doctors may attribute the child's complaints to psychological causes, they seldom can back up their opinions. School phobia, for example, is a manifestation of separation anxiety. Children with separation anxiety display symptoms when anticipating separation but which resolve when separation does not occur. In M.E., symptoms are present not only during school hours, but after school and on weekends as well. Also, symptoms such as fever, lymph node pain, night sweats, and muscle and joint pain are not features of school phobia. Those who are apt to diagnose depression run into the same inconsistencies. . . Children with M.E. can become depressed, but usually do so because no one believes they are ill. (Verillo & Gellman 1997, p. 327)

As one advocate writes, ‘The real losers in this blame game are the children. . . The focus [has shifted] away from the arduous and tedious work of making children well again. Let’s get on with it’ (Munson, M. 2000 p. 194).

**However inconvenient it may be, Myalgic Encephalomyelitis is a devastatingly severe physical illness with no cure, and more than a million victims who have had to put up with not only being severely ill but with abuse and social disbelief about their condition as well as an almost total lack of appropriate medical and other support. This has to stop.**

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

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

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

### **So what can you do to help?**

If you know someone with M.E. the first thing you can and must do is to start treating them as is appropriate for the illness they actually have; an organic illness similar to multiple sclerosis, Lupus and polio that can often be at least as disabling and severe as other serious diseases such as MS and Lupus and which can worsen in the short and long-term with repeated physical, cognitive or orthostatic overexertion.

People with M.E. have only a tiny minority of the medical, scientific, legal and other potentially supporting professions – or the public, including their own friends and family members – on their side. As the Committee for Justice and Recognition of Myalgic Encephalomyelitis explain:

There is no immunity to M.E. The next victim of this horrible disease could be your sister, your friend, your brother, your grandchildren, your neighbour [or] your co-worker. M.E. is an infectious disease that has become a widespread epidemic that is not going away. We must join together, alert the public and demand action (2007, [Online]).

The ‘CFS’ insurance scam *will* be fully exposed, there is no doubt about that. But the question of WHEN this will happen is entirely up to us, and how willing we are to stand up and refuse to accept this injustice any more. That is what is needed; people from all over the world to stand up for the truth about Myalgic Encephalomyelitis. Individual physicians, journalists, politicians, human rights campaigners, patients, families and friends of patients and the public – whether they are affected yet by M.E. or not. That is the only way change will occur; through education and people simply refusing to accept what is happening any more.

So PLEASE help to spread the truth about Myalgic Encephalomyelitis. This appalling abuse and neglect of so many severely ill people on such an industrial scale is truly *inhuman* and has already gone on for far too long. People with M.E. desperately need your help.

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### **For more information:**

- For more information about the medical and political facts of M.E. please see: What is Myalgic Encephalomyelitis? Extra extended version, Who benefits from ‘CFS’ and ‘ME/CFS’?, The misdiagnosis of CFS, Why the bogus disease category of ‘CFS’ must be abandoned, Smoke and mirrors, M.E. The Medical Facts - Extended, The ultra-comprehensive M.E. symptom list, Testing for Myalgic Encephalomyelitis and Putting research and articles into context
- For information on treatment of M.E. see: Treating M.E. - The Basics. See also Hospital or carer notes for M.E. and Why patients with severe M.E. are housebound and bedbound
- If you know someone with M.E. please see So you know someone with M.E.? and So you know someone with M.E.? Part 2: Tips on coping for friends, partners and family members. See also the new paper: M.E. vs MS: Similarities and differences which explains the many stark similarities between M.E. and MS medically, and the vast political and social differences between the two diseases.
- See also: Case Studies and What it feels like to have Myalgic Encephalomyelitis: A personal M.E. symptom list and description of M.E. To see some short videos about M.E. see the Video and Audio page.
- To read a list of all the articles on this site suitable for different groups such as M.E. patients, carers, friends and family, the ‘CFS’ misdiagnosed, doctors or severe M.E. patients and so on, see the Information Guides page.
- If you have an important general question about M.E. (or your friend or family member with M.E.) not answered on the site (and that isn’t about complex medical/diagnostic issues), please send it by email.
- What is an adrenaline surge? Adrenaline is often referred to as the ‘fight or flight’ hormone as it kicks into action in situations of potential danger. However, adrenaline also kicks in when the body is in physiological

difficulty, which is very often what is happening to severe M.E. sufferers. Adrenaline surges make the heart pump faster and raise the blood pressure, forcing blood around the body with greater force to supply the muscles with more oxygen, so that they can make a greater effort. Surges of adrenaline increase the metabolism. They also relax and dilate the airways so that more oxygen than usual can be taken in. Adrenaline surges can also decrease the amount of pain felt. As a result of all of these factors, adrenaline surges – while they last – have the ability to increase physical speed, strength and other physical abilities. Unfortunately, when these bursts of adrenaline wear off – as they must – people with M.E. are left far more ill as a result for many days, weeks, months or even years. People with M.E. are harmed by adrenaline surges, both by the physiological stress to the body of the changes caused by adrenaline, and by the extra activity which adrenaline enables, which may be far beyond the body's normal limits so that such activity causes damage. For every short term 'gain' there is a far greater loss overall.

For more information on adrenaline surges in M.E., and the different order in which certain bodily systems may be affected by M.E. (and by overexertion), see [The effects of CBT and GET on patients with Myalgic Encephalomyelitis](#) or [Treating Myalgic Encephalomyelitis - Avoiding Overexertion](#).

## References

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

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

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*"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

*"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."* Margaret Mead (1901-78)

*'Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. The CDC definition is not a disease process.'* Dr Byron Hyde 2006

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

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

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

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

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

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*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 million stories untold – Summary of the key points

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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.

3. 'CFS' is a medical fraud, created (and maintained) for political and financial gain by vested interest groups. People with M.E. are *not* being mistreated because of a lack of scientific evidence, there is an abundance of evidence spanning 70 years which proves beyond any doubt that M.E. is a distinct organic neurological disease. Accordingly, Myalgic Encephalomyelitis has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. This code remains unchanged today.

4. Medically, M.E. is very similar to diseases such as multiple sclerosis. See the new [M.E. vs MS: Similarities and differences](#) paper for details.

5. All people with M.E. want is to be treated based on the available science, and to have their fair share of the resources available to those with medically (if not politically) comparable illnesses such as multiple sclerosis or motor neurone disease etc. Sadly this is not happening now, and patients are being mistreated based on political and financial considerations and the science AND REALITY is being ignored.

6. Please help to spread the truth about M.E. and the difference between M.E. and 'CFS.' Knowledge is power.

The most important facts to remember when dealing with your friend, family member or partner with M.E. are:

**a. Try not to make superficial judgements of ability or severity!** One can probably observe people with some illnesses carefully for an hour or so and collect a lot of good information about what they can and can't do, how severe their illness is, and what their usual symptoms are from day to day, and so on. However M.E. is not one of those illnesses. M.E. is *not* a stable illness.

Observing the average M.E. sufferer for an hour – or even a week or more – will not give an accurate indication of their usual activity level because the severity of M.E. can wax and wane throughout the month, week, day and even hour. Also, people with M.E. can sometimes operate significantly above their actual illness level for short periods of time thanks to surges of adrenaline – albeit at the cost of severe and prolonged worsening of the illness afterward. Relapses and worsening of symptoms are also very often also significantly delayed (there may be both an acute AND a delayed reaction).

Just observing someone with M.E. do a certain task should not be taken to mean (a) that they can necessarily repeat the task anytime soon, (b) that they would have been able to do it at any other time of day, (c) that they can do the same task every hour, day or even every week, or month, or (d) that they won't be made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task. Often a considerable rest period is needed before and after a task, which may be hours, days, weeks or months long. For example, someone may need 2 weeks rest before an outing, for example, and may then spend 3 weeks extremely ill afterwards recovering from it. Just observing them in the 2 hours they were 'out and about and mobile' is of course not at all representative of their usual ability levels.)

Most importantly, because the worsening of the illness caused by overexertion may not even begin until 48 or more hours afterwards (when most observers are long gone), it's impossible to tell by seeing an M.E. patient engaged in an activity, whether that activity is so far beyond the patient's limits that it will end up causing a severe or even permanent worsening of the illness (or 'relapse'). To be blunt, the activity may even end up killing the patient. This isn't common (the death rate is estimated at 3%), but deaths can and do occur. Thus, observers who see an M.E. patient engaged in an activity have no idea what the consequences of this activity may be.

One simply cannot know a M.E. sufferer's usual ability level or severity level unless you have observed them over a very long period of time, or actually **asked** the person detailed questions about what their average daily activity limits, abilities and symptoms are. Short-term and superficial judgements of ability and disability levels in people with M.E. are ill-advised. Appearances are almost always very deceiving with M.E.

See [The M.E. Symptom List](#) for more information. See also: [Why patients with severe M.E. are housebound and bedbound](#) and [Hospital or carer notes for M.E.](#)

**b. Encouraging your friend or family member to be more active when they have M.E. is not helpful, or kind.** Even trivial levels of activity over their individual post-illness limits can cause severe relapse or leave them wheelchair bound, or bedbound for many long *years* afterward, or permanently – and you do NOT want that on your conscience. Overexertion can also cause death in M.E. (often due to cardiac insufficiency), again, you do NOT want such a tragic outcome on your conscience. Increasing activity levels is something every person with M.E. will do the second they are able to, trust me! But arbitrarily increasing their activity levels above what they can cope with can only ever be counterproductive. It's a bit like telling someone with two broken legs to take up jogging, extremely painful, damaging and cruel – and of no possible benefit.

**c. Telling your friend or family member to 'think themselves well' when they have M.E. is not helpful, or kind or reasonable.** There is no more possibility that M.E. could be improved by positive thinking or willpower any more than with multiple sclerosis or Parkinson's disease. If there were, we would ALREADY no longer be ill – there is nothing on earth more motivating than not wanting to have M.E. any more. But personality types and attitudes have nothing to do with the prognosis of M.E., any more than with these other illnesses. Studies showing positive outcomes for exercise and positive thinking (GET and CBT) on tired people are irrelevant to people with M.E., or those with any other distinct illness. Telling someone with a serious organic illness that they are only ill because 'they think they are' or that they could 'think themselves well' if they really tried hard enough is abusive, and incredibly cruel.

For more information see: [The effects of CBT and GET on patients with Myalgic Encephalomyelitis and Comments on the 'Lightning Process' \(etc.\) scam](#)

**d. M.E. is a serious neurological disease. Treat your friend or family member** no differently than you would treat them if they had [multiple sclerosis](#) or any other serious disease. Treat them how you would want to be treated if it were you that was unlucky enough to contact M.E., instead of them. M.E. is hell, but with no support from friends and family it can be made so much worse.

M.E. is a hellish disease, but the good news is that you really do have the power to make an enormous positive difference to the person you know with M.E. – just by being there for them and offering practical and/or emotional support but also by helping them avoid overexertion as much as possible and so have their best possible prognosis.

For more information on practical ways you can help with this process, see [Hospital or carer notes for M.E.](#)

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## 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 damage is an essential part of 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 Organization's International Classification of Diseases since 1969 as a distinct organic neurological disease. M.E. is classified in the current WHO International Classification of Diseases with the neurological 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 that exists. 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 barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input. This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death. If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive. *M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*
- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than one 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.