

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

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

M.E. - The shocking disease

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In thinking about M.E. and all of the terrible things that are happening so unfairly to so many wonderful innocent people year after year, and how extremely severe a disease it can be physically, I keep coming back to one word: shocking. These are the basic M.E. facts:

- M.E. is similar in significant ways to illnesses such as multiple sclerosis (M.S.), Lupus and Polio.
- M.E. occurs in epidemic and sporadic forms, over 60 M.E. outbreaks have been recorded worldwide since 1934.
- What defines M.E. is a specific type of acquired damage to the brain (the central nervous system) caused by a virus (an enterovirus). It is an *acute (sudden) onset* neurological disease initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem.
- 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.
- M.E. is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- M.E. can be more disabling than M.S. 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. In some cases M.E. is fatal.
- 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 (e.g. 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.

- M.E. is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose, even within just a few weeks of onset, using a series of objective tests.
- M.E. is a debilitating neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.
- Many patients with M.E. do not have access to even basic appropriate medical care. Medical abuse and neglect is also extremely common and often results in the disease becoming severe (and in some cases, death is caused).
- Governments around the world are currently spending \$0 a year on M.E. research.

these facts however, fall far short of getting across what a hell on earth M.E. really is. Above all else, I think M.E. is a shocking disease. These are a few of the biggest shocks I've faced, and that others with M.E. also experience:

1. The shock of extremely severe sudden illness and disability

The first big shock is how quickly and completely your entire life can change forever. Having your body suddenly act very differently and not be able to do all the things you have done many thousands or millions of times before, is surreal. This is especially so when this occurs suddenly from one day to the next, as it does with M.E. The sense of unreality can be so strong that you almost wonder why everyone else is still going on as if nothing had changed and everything was normal.

For me, in March 1995 at the age of 19, I went from being very healthy and happy one day to having problems standing upright for more than a few minutes at a time,

the next. I also suddenly had severe problems sleeping, thinking and remembering, speaking and understanding speech, eating many foods that I previously tolerated perfectly well, coping with even low levels of noise and light and vibration, coping with warm weather, sitting, with my heart and blood pressure, with any type of physical or cognitive activity causing severe relapse unless within very strict limits as well as memory loss, facial agnosia, learning difficulties, severe pain, alcohol intolerance, blackouts and seizures, intense unusual headaches, burning eyes and ear pain, rashes (and other skin problems), severe nausea and vertigo, total loss of balance when I closed my eyes or the room was dark, muscle weakness and paralysis, and so on.

I suddenly had over 60 individual symptoms, and could only do 40% or less of my pre-illness activities.

It's a bit like one day waking up and suddenly everyone around you is speaking another language and looking at you strangely for not being able to understand what is being said.

At first, not only is it very hard to just accept, but also to really believe it is happening, and that it won't just go away as suddenly as it came. It's all just such a big shock.

2. The medical system shock

As if that weren't enough all on its own, the next big shock involves lifelong beliefs about our medical system. You soon find out that the disease you have is one of those that is treated differently from many others, that not every disease is viewed equally, and that bizarrely this has *nothing at all* to do with the type of disease or the severity of the disease or its symptoms, or testable abnormalities, or the possibility of death, but other non-scientific and non-medical factors. It has to do with political and financial factors, and marketing.

You find out that some diseases get you 'red carpet' treatment or and guarantee that you are treated very well, others are treated adequately, and unfortunately several leave you with no real care at all. Even worse, some diagnoses subject you to serious mistreatment from the professionals *meant to be there to help you*.

Most people trust absolutely that if they get severely ill, they can go to an emergency room and be given the appropriate medical care. I used to trust in that too. But I was to soon find out the hard way that that didn't apply to me anymore. If I went to the emergency room, there was an enormous chance I'd not only get no help at all, but be ridiculed into the bargain or told 'to stop exaggerating' or refused the appropriate tests (and have older test results ignored). I may then be told, illogically, and despite all the evidence to the contrary that 'there is nothing wrong with you, go home and let us care for someone who is really ill.' I'd be far more likely to come out of the

emergency room far sicker than when I'd gone in (in crisis), as well as being verbally abused and insulted as well.

Dealing with GPs and specialists is much the same most of the time, for those with M.E. Probably the most common treatment recommended to patients with M.E. is graded exercise therapy (GET) (Both formal and informal programs). This is a 'treatment' that can and very often does leave M.E. patients, including children, far sicker afterwards for months, years or longer (wheelchair-reliant, bedbound, needing intensive care etc.). It can also cause death. While it may help some of those with other illnesses very different to M.E., it has a ZERO percent chance of providing any benefit to M.E. patients. If even a tiny percentage, say 2%, of almost any other patient group were made as ill and disabled by any treatment (as M.E. patients are by GET) it would be a huge scandal. It would make all the papers and there would be all sorts of legal actions and enquiries, and outpourings of public outrage. Yet the incidence of M.E. patients being recommended, or forced or coerced, into this torture is growing every year. Nobody much cares or even knows. It's more than shocking or just very cruel, it's obscene.

Most people have no idea that all this medical abuse occurs regularly, to people *just as ill or even far more ill* as those with M.S. or Lupus. When you do try to tell them, most often they refuse to believe it could be true, so strong is their belief in the fairness and logic of our health system and how much thought, objectivity and careful investigation supposedly goes into giving a final diagnosis and recommending treatment. It's a shocking loss, this loss of belief in a health safety net and a medical system based on logic, science and due care. It's such a comforting belief, it's hardly surprising people don't want to give it up, even if it is false.

Thanks to inappropriate medical care, I, as with many other M.E. patients, soon struggled to do even 5% of the activities I had pre-illness. I was made housebound and 99% bedbound, and have remained so for the last 10 years. My heart-rate skyrockets and my blood pressure drops dramatically after just a few minutes of standing or other overexerting activity. It feels like a heart attack in every organ, and as if my heart is about to explode, or just stop. (The highest heart-rate measurement I've had is 170 bpm and the lowest blood pressure measurement is 79/59 – both were taken at times when I was only moderately ill, relatively speaking, nowhere near my most severe state. Scary.)

I have spent most of the last decade, alone and in pain in a dark quiet room, coping with many different and hideous symptoms. I accept that some people get ill, and that I am at risk of this as much as anyone. What is hard to take is that, like so many M.E. patients, my reaching such a severe disability level and losing so much of my life was completely unnecessary and would very likely not have happened had I had even the most basic appropriate support in the beginning.

3. The welfare system shock

Despite being extremely ill and disabled, M.E. patients are often shocked to find that getting the basic welfare payments is very difficult or impossible. Bizarrely enough, the system is set up in such a way that you can actually be *too ill* to qualify, as so many hoops are required to be jumped through to lodge a successful claim, without which the claim is denied. Ironically, the government agencies seem to have little interest in this conundrum, nor in how much sicker jumping through all their hoops makes you long-term. The ignorance of doctors and their inability to give you an unbiased examination is also a huge problem.

Again, what is far more important to them is the name and reputation of your disease, not how ill and disabled you are. It is not uncommon to find instances of M.E. patients living for years with no disability payments, having to live on the mercy of family, or becoming homeless.

4. The media shock

The public largely trusts the information given about different diseases in the media. I did too, and I still do largely, provided the article is about M.S. or cancer. But like many M.E. patients, I was shocked to find out that when it came to diseases like mine, there was no onus at all on the reporter to be accurate. While a furore would ensure if articles made up *entirely* of false information were printed about M.S. or cancer, almost every article that I read about M.E. was of an unbelievably low standard, yet nobody seemed to care at all.

Similarly, the outrage when certain groups are made fun of in what is deemed an offensive manner, simply does not occur when it's M.E. that is being ridiculed. For some reason M.E. patients (in the UK particularly) are fair game. This is because despite the fact that our governments have created laws designed to stop discrimination on the basis of gender, race and disability and so on, discrimination against M.E. patients is not only allowed, but is actively supported and promoted by government. (For information on *why* this occurs, see [What is M.E.?](#))

5. The human rights groups shock

While the big human rights groups seem very eager to help many other groups and even individuals facing small or large problems, they seem completely unwilling to even look at the severe abuse of human rights facing perhaps a million M.E. patients worldwide, let alone do anything at all to actually help. This when even the smallest action on their part, the smallest indication of support for the M.E. cause, would be such a huge step forward for the cause. Such ignorance and injustice is shocking.

6. The friends and family shock

What makes coping with all these things unimaginably worse is having to do so with little if any support from friends and family – and even while facing abuse or ridicule from friends and family. Some patients are even disowned by their whole family, or all but a few members.

Loved ones often believe the same financially-motivated media and government-sanctioned nonsense about your disease as the doctors do. They often accept the ‘miracle cure’ stories in the media featuring people with a hundred different mild (and sometimes psychological) or transient diseases jumping up and down about how they have been ‘cured’ by the mumbo jumbo money-making scam of the week – despite the fact that NONE of these stories features actual M.E. patients, or even patients with diseases similar to M.E.

It’s such a huge shock that those you love could see you so ill and refuse to support you and that they have more trust in doctors than in your integrity. They can’t believe that if you were seriously ill, a doctor could miss it, even though that is exactly what has happened. They can’t believe that the media would be allowed to print completely fictional information about your disease often based on mixed and *entirely unrelated* patient groups, even though they *are* doing just that. Not having medical or media (or government) support makes getting support from loved ones almost impossible.

Having loved ones not stand by you hurts a lot, in many ways. It takes yet another huge swipe at what self-esteem you have left after being treated like dirt by your trusted doctors and welfare departments, leaving study incomplete and/or losing your job and your ability to support yourself and/or being denied the services of a carer when you urgently need one. After so many attacks on your integrity and worth you can’t help but be worn down by it all, Particularly when you’re so ill and even more so if you are not yet of adult age when you become ill. You inevitably feel, not depressed, but as if you must personally be unworthy somehow of any type of care or compassion. Such messages inevitably sink in to some extent after constant repetition, no matter how educated, strong or mentally fit you are.

7. The M.E. charities and support groups shock

Realising that very nearly all of the charities and support groups that claim to be there to help you actually do not represent or support you at all and are actually hostile to your interests is yet another huge shock.

You go to a group that you trust finally to give you the unadulterated facts and to be working towards improving things and all you get is more abuse and misinformation. Just as bad, you also don’t get all the important information about M.E. that could make an enormous positive difference to your life and to your health. If you try to

improve matters and provide these groups and individuals with accurate information you are either ignored or banned, perceived as negative.

M.E. patients are in a terrible position. Almost all ‘our’ charities have sold themselves off to the highest bidder, and are now working to promote the same harmful misinformation they were created to fight against. (The concepts of ‘CFS’ and ‘ME/CFS’ can be immensely profitable to some groups, as is explained in several other HFME papers.) These groups claim to be representing a large and diverse patient group but in reality they do not work for the benefit of any group, except themselves. They often take advantage of patients’ lack of ability (or unwillingness) to engage with politics, to read and assimilate significant amounts of slightly complex text and of their goodwill and trust, in the cruellest way. Many patients put all their faith and efforts into this false advocacy, led by vested interest groups. Many (perhaps even most) fellow patients are, unwittingly, working directly against their own interests and aiding their abusers. Many seem determined to support the same old illogical nonsense that is the reason that no progress at all has been made in over 20 years. Perhaps some patients are too ill to even investigate other sources of information than the charity, or they have taken the charity’s word for it that the (entirely bogus) information they provide is all that exists.

These sell-out groups and individuals are at fault here to a large extent, but at the same time they couldn’t keep doing the evil things they do if they didn’t have so much undeserved (and extremely unwise) patient support. It’s so incredibly shocking, and *frustrating*.

Those few groups and individuals that are involved in genuine advocacy are often able to do very little due to the physical constraints of M.E., the poverty associated with M.E., and the lack of public and other support. M.E. patients are just too ill to fight effectively for themselves like AIDS patients did. They can’t rally or march and many can only barely read or write now. AIDS patients also often have an early asymptomatic period of illness, which enables significant contribution to activism – but for M.E. patients the severe symptoms begin on day one.

8. The M.E. advocacy nightmare shock

Perhaps most shockingly of all, when you try to do some advocacy yourself and tell people about the double standards, discrimination and unfair treatment, and show them mountains of solid facts, you are met with disbelief. People cannot or will not believe that doctors could be so cruel, unscientific, ignorant and illogical; or that our governments and media could be so unethical and dishonest by selling their integrity for political and financial gain; or that so-called ‘charities’ could be just as corrupt.

Many people refuse to even do a tiny bit of quality reading on the topic of M.E., wrongly believing that they already have all the facts and know all there is to know, believing that anything that they don’t know just can’t be true. If you try to give

people correct information you are accused of exaggerating or being fanciful. People snicker or roll their eyes when you talk about cover-ups, and give your information as much credence as stories of alien abductions or the ‘false’ moon landing. Anything not already mainstream is met with scepticism, as is the idea that all of these groups could *collaborate* to create a mutually profitable, and very hard to undermine, lie. Despite ample evidence of similar scandals and cover-ups in the past, people seem unwilling to give up their belief in a fair and just government, media and medical system. They refuse to give up their comforting delusions...until and unless something similar happens to them, at least, and they have no choice but to face reality. But then, of course, they too are disbelieved when they try to spread the word, and so on and on it goes.

Most families and friends of patients are completely unwilling to help with advocacy, very often due to ignorance about the medical and political facts of M.E. Others are too busy with the duties of a carer for advocacy. Patients with other diseases almost always do not understand that the most commonly given information on M.E. is entirely false. By believing M.E. is something it is not and reinforcing many of the worst myths about the disease, most of these well-meaning groups and individuals work directly against the interests of M.E. patients, sadly.

M.E. itself also seems to work against you, in an unexpected way. People say it’s too severe and there are too many symptoms. The entirely unique way we respond to even trivial exertion and are so disabled by it, instead of inspiring sympathy, seems to actually inspire disbelief. People seem to (bizarrely) believe that there must be some limit on how bad a disease could be, and that such severe illness couldn’t be possible long-term. That you couldn’t possibly be too ill to sit or stand up, use the phone, speak or be spoken to, listen to music, write a letter, spend time in hospital or take a short trip out of the house; That you couldn’t possibly be so ill that you can only dream of one day being *well enough* to use an electric wheelchair sometimes, if you’re really lucky – and so on. As if all humans were ‘guaranteed’ somehow to always be able to at least do such simple tasks, and to only ever suffer a ‘reasonable’ level or time period of disability. But the body does not acknowledge such limits. If only.

in 20 years not only has no progress been made in the fight for basic rights, but things have become much worse for M.E. patients and they continue to grow worse still as the years pass.

M.E. is a shocking disease in every way.

M.E. is at least as disabling as any of the other very serious diseases (such as M.S.) and the extremely high level of suffering and isolation it causes can last for many years or decades at a time. Yet M.E. patients get the least amount of support and compassion and such high levels of abuse and outright *ridicule*.

Some of us have some family and/or friends on board, some have welfare, some have basic medical care (although almost none have the same level of care the average M.S. patient has). But most don't have all or even most of these things and when they do they have often taken many years to get and are very hard won.

By the time many of us have some of these things we have been made severely ill by going so long without the right care, that it's a somewhat hollow victory. Especially when we also know that so many others aren't so lucky and that every year thousands of patients, adults as well as teenagers and very young children, are still needlessly being made severely ill or dead through ignorance and misinformation.

It's like an episode of 'The Twilight Zone.' You want to wake up screaming some mornings, thinking it's a nightmare and that such a hell just couldn't possibly be real. That so many innocent people could be so ill, abused and persecuted, with almost none of the public even caring or knowing. That such a flimsy and unethical global medical scam couldn't be so successful at fooling almost everyone, despite the fact it's based on nothing more than smoke and mirrors, scientifically speaking. It's all just far too shocking to take in sometimes.

I invite readers to be shocked about what is happening, even if M.E. hasn't yet affected someone you love or know. The facts are profoundly shocking – I haven't explained even half of them here.

If you have the facts about M.E. you should be not only shocked by what is happening, but also appalled, disgusted and outraged. I beg you to please use that shock, act on it and use it to help try and change things, and to see M.E. patients finally get some basic fair treatment and justice.

The only way change will occur is through education, with enough people simply refusing to accept what is happening anymore.

M.E. patients need your help so desperately, right now.

Thank you, sincerely, for taking the time to read this paper.

More information:

- For more information on all aspects of M.E., including what you can do to help M.E. patients' desperate fight for justice and fair treatment, and for references for this text, please see: [What is M.E.? A historical, medical and political overview.](#) See also: [Why care about M.E.?](#) and [Smoke and Mirrors.](#)
- [M.E. vs MS](#) explains the many medical similarities and political differences between the two diseases.

- To read a list of all the articles on this site suitable for different groups such as M.E. patients, carers, friends and family, members of the public, doctors and so on, see the [Information Guides](#) page.
- HFME is a new international charity run for and by M.E. patients. Most contributors are very ill and disabled. For more information about HFME please see www.hfme.org

Acknowledgments

Thanks to Emma Searle, Lesley Ben and Peter Bassett for editing this paper. Thank you to also to Kate W. for her contributions to this paper.

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Relevant quotes

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

PROFESSOR HOOPER 2003

‘The term myalgic encephalomyelitis 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

‘Myalgic Encephalomyelitis (M.E.) is distinguished by a unique clinical and epidemiological pattern characteristic of enteroviral infection. It has an UNIQUE Neuro-hormonal profile.’

DR ELIZABETH DOWSETT

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

DR MELVIN RAMSAY (ON MYALGIC ENCEPHALOMYELITIS)

‘Modern medicine is not scientific, it is full of prejudice, illogic and susceptible to advertising. Doctors are not taught to reason, they are programmed to believe in whatever their medical schools teach them and the leading doctors tell them. Over the past 20 years the drug companies have taken medicine over and now control its

research, what is taught and the information released to the public.’

ABRAM HOFFER MD

‘Central nervous system dysfunction, and in particular, inconsistent CNS dysfunction is, undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process. Of the CNS dysfunctions, cognitive dysfunction is one of the most disabling characteristics of ME. When this simple fact is understood, it become immediately apparent why this is such a devastating disease for children, students and adults, both within and outside the educational system. Today, few work situations exist where consistent use of education and developed cognitive skills are not necessary to maintain a place in the work force. When the patient consistently has difficulty in making new memories, recalling old memories and coordinating new and old information he becomes of little use in the modern work force. It is the combination of the chronicity, the dysfunctions, and the instability, the lack of dependability of these functions that creates ‘the most chronic of chronic disabilities.’ It is these combined acquired, chronic brain and physical dysfunctions that define M.E.’

BYRON HYDE MD AND ANIL JAIN MD IN ‘THE CLINICAL AND SCIENTIFIC BASIS OF M.E. P 43

‘Suppose that, in the 'bad old days' before polio vaccination, a parent whose child had died had been told: "She stopped breathing on purpose you know." A public outcry would surely have ensued. And imagine if the next remark had been: "Tell me, did you encourage her in this belief that she couldn't breathe?" The mere idea of such an attitude, quite properly, takes the breath away. Yet children with severe M.E., unable to walk or even to eat, are often considered to be shamming and all sorts of bizarre strategies have been used to try to expose this.’

JANE COLBY IN 'M.E.: THE NEW PLAGUE' P.22

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

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. See: What is M.E.? or the References page for more information or for references.



This paper is included in the new *Caring for the M.E. Patient* book by Jodi Bassett.

The book also includes a Foreword by the world's most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the *HFME Books* page on www.hfme.org

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

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UPDATED JUNE 2011. TAKEN FROM WWW.HFME.ORG



- Myalgic Encephalomyelitis (M.E.) is a disabling neurological disease that is very similar to Multiple Sclerosis (M.S.) and Poliomyelitis. Earlier names for M.E. were 'atypical Multiple Sclerosis' and 'atypical Polio.'
- M.E. 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, tis = 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. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.
- M.E. 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.
- M.E. 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.
- M.E. can be more disabling than M.S. 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 M.E. 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 (e.g. 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.*

- M.E. 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 (e.g. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- M.E. 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.