

## 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.

### Are we just marking time? Why are we waiting to act when tests for M.E. exist RIGHT NOW, and the need for activism/action is so very urgent?

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Sometimes comments are made by some advocates about the lack of a unique diagnostic test for Myalgic Encephalomyelitis, comments like:

*“Until there is a single specific test for M.E., M.E. will not (and can not) be taken seriously...”*

*“Until there is a specific marker for M.E., researchers will not/ can not separate out M.E. patients from those with various unrelated ‘fatiguing illnesses’ in their studies, unfortunately...”*

*“M.E. will be seen as psychological until we have a unique marker that proves that it’s a real disease ...”*

*“The only way things will improve for people with M.E. is if research can give us a specific test for M.E. We must put everything we can into medical research. Only further research and a test will give us the respect and legitimacy we desperately need...”*

There are a number of serious flaws with this approach, including the following four main points (that will each be expanded upon in the main text):

- **There may never be a specific marker for M.E. or we may not have one for decades**, as with MS and Lupus and so on
- **These comments seriously undermine the credibility of all the existing M.E. research**; when the reality is that the evidence for neurological M.E. is rock solid and spans over 70 years.
- **Even if we had a unique single test, this would change little or nothing**, this piece of evidence would just be ignored or misrepresented like the many hundreds of equally conclusive pieces of evidence that we already have. Because this isn’t and never was about science, it has always been about politics and MONEY.

But most compelling of all is point 4:

- **We already have a SERIES of objective tests that allow M.E. to be reliably diagnosed** – in a manner similar to the way MS and Lupus are diagnosed – RIGHT NOW!

#### **1. There may never be a specific marker for M.E. or we may not have one for decades**

Enormous sums of money have been spent searching for markers specific to MS, Lupus, and cervical cancer – as well as a vast number of other diseases – over many years and decades and have been entirely unsuccessful.

Of course, so very little time and money has been spent researching genuine neurological M.E. patients and looking for the unique markers of M.E. that we may indeed find that the task is a simple one and easily completed within a short time frame. This is a very real possibility.

BUT, the possibility that we may NEVER find a unique marker for M.E. present in 100% of cases must also always be taken into account. This is also a real possibility.

(This second possibility is also made far more likely – or even a certainty – due to the fact that there are almost no studies being conducted using a 100% M.E. patient population these days:, because of the bogus disease category of ‘CFS’ and the newer but equally flawed concept of ‘ME/CFS.’)

You don’t see people with Multiple Sclerosis commenting that of course nobody can be expected to take MS seriously or do legitimate MS research involving only MS patients until there is a specific MS marker, do you? Or people who have Lupus or cervical cancer? So why is M.E. somehow different? Scientifically at least, M.E. isn’t.

There are of course no tests which can be used to confirm a (mis)diagnosis of ‘CFS,’ but ‘CFS’ and M.E. are very different entities.

## **2. These comments seriously undermine the credibility of all the existing M.E. research**

These comments imply that the science supporting the fact that M.E. is a distinct organic neurological disease is nonexistent, or 'shaky' in some way. The reality of course is that the science is very clear that M.E. is a distinct organic neurological disease, and it has been since at least 1969 when the World Health Organisation classified M.E. as an organic neurological disorder in their International Classification of Diseases.

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. There is enough objective scientific evidence to prove the basic facts of infectious, virally induced, acute onset neurological M.E. as per Ramsay and Hyde and the more than 60 documented outbreaks worldwide etc. many hundreds of times over. (For more information see [What is M.E.? Extra extended version.](#))

These comments about our need for a unique diagnostic test before we can expect to be given legitimacy also absolve those perpetuating serious abuses of M.E. patients of blame – and so remove any impetus for them to stop the enormous harm they are causing. These comments imply that these groups and individuals dishonest and criminal actions are merely a reasonable response to genuine scientific uncertainty. This is a very bad idea when the reality is that of course what these vested interest groups are doing is not 'reasonable' or 'understandable'... it is politically and financially motivated inhuman abuse and outright medical fraud on a massive scale. It's a fraud we need to try to expose as much as possible in order to end it: rather than in any way to excuse or ignore it.

## **3. Even if we had a unique single test, this would change little or nothing**

Even if there were a specific diagnostic test for M.E. discovered, there is no reason whatsoever to presume that this piece of evidence would not be ignored or misrepresented like the many hundreds of equally conclusive pieces of evidence that we already have. Of course it would be!

There was enough hard evidence proving the organic and serious neurological nature of M.E. many decades before the bogus disease category of 'CFS' was even created. 'CFS' is 'medically unexplained' or 'unexplainable' and 'mysterious' but genuine M.E. isn't *and never was*. Right from the start this was never a scientific battle, it has always been a political one. If the overwhelming evidence spanning over 70 years of severe testable abnormalities, viral causation, more than 60 outbreaks and even the many deaths from M.E. weren't enough, nothing ever will be. No amount of science alone will ever get us out of this mess. If it could have, it would have already, as the science has been there for decades. If this were about science, indeed the definitions of 'CFS' would never have been created in the first place. (See: [Who benefits from 'CFS' and 'ME/CFS'?](#) for more information.)

Yes, patients got rid of the 'hysterical paralysis' tag when it was proved that Multiple Sclerosis was an organic neurological disease, but what is happening with M.E. is completely different. We cannot stop our abuse in the same way, because in our case it happened the other way around; we had the evidence M.E. was an organic neurological disease already BEFORE the vested interest groups even got involved.

**The problem we face is not that we don't have enough scientific evidence, but that all the overwhelming evidence we do have is being purposefully ignored for mere political and financial gain.**

## **4. We already have a SERIES of tests that allow M.E. to be reliably diagnosed**

Most compelling of all, there are actually a series of objective tests which readily allow a diagnosis of M.E. to be confirmed – in a manner similar to the way MS and Lupus are diagnosed – RIGHT NOW!

If all tests are normal then a person does NOT have M.E. That is a fact. M.E. is a distinct easily recognisable and testable disease with a number of unique features, it is not merely a diagnosis of exclusion as 'CFS' is. These tests which together can confirm a M.E. diagnosis include:

SPECT and xenon SPECT scans of the brain, MRI and PET scans of the brain, neurological examination, neuropsychological testing (including QEEG scans) and the Romberg or tandem Romberg test, various tests of the immune system (including tests of natural killer cells), insulin levels and glucose tolerance tests, sedimentation rate testing, circulating blood volume tests, 24 hour Holter monitor testing, tilt table examination, exercise testing and chemical stress tests, and physical exam.

On a purely scientific level, we have more than enough information to reliably diagnose patients with M.E. using objective tests (and by taking detailed case notes and conducting a detailed physical exam etc.) within just a few weeks of the onset of the disease. If the will and the funding were there, scientists could right now very easily make sure that studies contained a 100% M.E. population – just as they do with MS patients or patients with Lupus and so on. Scientifically, it would be no more difficult to do this for M.E. than with these other diseases. For more information see: [Testing for M.E.](#) and Dr Hyde's [The Nightingale Definition of M.E.](#)

The problem is not that these tests don't exist, but that doctors – and many patients – are unaware of this information on testing, that it is not generally accepted due to the nefarious influence of political and financial vested interest groups, and that there are overwhelming financial and political incentives for researchers to IGNORE this evidence in favour of the bogus 'CFS' (or 'subgroups of 'ME/CFS') construct, and so on.

### **In conclusion...**

M.E. is not difficult to diagnose, or to distinguish from 'CFS' or any other fatiguing illnesses. M.E. is also not 'difficult to define' or 'mysterious' or 'medically unexplained' or a mere 'diagnosis of exclusion.' These are characteristics of 'CFS' but not of M.E.

**M.E. is no more difficult to diagnose through using a series of tests than is MS.** In fact, it has been suggested that M.E. diagnosis is significantly less difficult and more reliable than that of MS! We can also be a lot more certain about the cause of M.E., compared to MS. The cause of MS is hotly debated, while the fact that M.E. is caused by a virus is well established beyond doubt and there is overwhelming evidence that M.E. is caused by an enterovirus. (See [M.E. vs MS: Similarities and differences.](#))

This 'we need to wait for a test and more science before we can expect any real change' approach to M.E. advocacy does us no favours. There are so many enormous hurdles facing people with M.E., and M.E. activism and advocacy. At times it seems overwhelming.....and it is overwhelming, but especially so when additional hurdles are put needlessly in place by us.

Yes, having an idiot-proof one-step diagnostic test would be wonderful, and of course we should do what we can to make that happen. But to imply that we can't expect much to change until we have such a test is madness: especially when **M.E. can be reliably diagnosed using a series of tests, RIGHT NOW.** (See: [Testing for M.E.](#) for more information on these tests.)

We are fighting so many powerful and influential groups, but what we have on our side is ethics, reality and SCIENCE. That is HUGE for us. Even with all their power and money we have a truly enormous advantage over them; but only if we use it. The truth has to win out in the end, but we have to let it!

We must act now with the abundance of science we have, there is no need to wait endlessly for more. We must dedicate ourselves to not ever compromising on the facts of M.E., and doing everything we can to get the facts out there. This is a political battle. We also need to know enough not to work against our interests by promoting harmful propaganda to the public as if it were fact, and to refuse to support groups and individuals who are guilty of this. That is the only way we will get anywhere. (We also need far more doctors and others to have the guts, intelligence and integrity to do the same, it goes without saying. We can't do this alone.) The unadulterated scientific facts about M.E. are mind blowing and utterly compelling and credible, but the 'CFS' and 'ME/CFS' propaganda isn't.

There will never be a better time to act than NOW. Things are only getting worse for us as time goes on, not better. People with M.E. are being horrifically abused and neglected by the medical profession and even friends and family. They are suffering horribly and dying horribly (often needlessly) every minute of every day. There is no time for any of us to waste just 'marking time.'

### **Additional notes on this text:**

- The basic facts are that 'CFS' and M.E. are not at all the same thing:
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.

There is also no such disease as 'ME/CFS' or 'CFS/ME' or CFIDS and so on. The distinction must be made between terminology and definitions. The terms are all often used interchangeably, but the definitions of each term are very clear and distinct. For more information see: [What is Myalgic Encephalomyelitis? A historical, medical and political overview](#) and [The Terminology Explained](#)

- ***Almost nobody is studying genuine M.E. patient groups anymore, note:*** Even groups such as MERGE in the UK, which once focused exclusively on genuine M.E. have recently come out and said that they no longer have the desire to even attempt to study 100% M.E. patient groups (as per Ramsay and Hyde and the long history of M.E. etc.) but instead they plan to look at subgroups of what they call 'ME/CFS' – which means in fact subgroups of 'CFS.' But this study of mixed fatigued patient groups will help nobody, least of all M.E. patients which are unlikely to even be involved at all, let alone in a meaningful way. (Considering this shocking change, one wonders what right they have to continue to retain the use of the term M.E. in any context. If you want to study groups of fatigue illnesses, you are of course free to do so, but you cannot ethically and scientifically claim at the same time that what you are saying relates to M.E.!) For more information see: [MERGE, 'ME/CFS' and 'CFS.'](#) These comments also apply to Kerr's recent '7 genetic subtypes of 'ME/CFS.' There is no evidence at all that even one of these groups is M.E., let alone more than one. None of the groups described sounds even similar to M.E. and patients were selected merely on the presence of 'fatigue.' Such fatigue-based non-M.E. research does not currently deserve support from the M.E. community.
- ***A note on so-called 'subgroups' of 'ME/CFS':*** 'ME/CFS' is just a diversion from the real issues instigated by vested interest groups, the same is true of 'sub-grouping ME/CFS.' It is a nonsense that makes a mockery of legitimate activism – don't fall for it. The only relevant subgroups here are M.E., and not M.E. People with Fibromyalgia have FM, and should be diagnosed with FM. To say that FM is a subgroup of 'CFS' or 'ME/CFS' is ridiculous. The same is true of post viral fatigue syndromes caused by Glandular Fever/Mononucleosis, Hepatitis, Ross river virus, Q fever or EBV – and so on. If you have a post-viral fatigue syndrome then that is your correct diagnosis, not 'CFS' or 'CFIDS' or 'ME/CFS' or anything else. For more information see: [Why the bogus disease category of 'CFS' must be abandoned](#) and [Problems with the use of 'ME/CFS' by M.E. advocates](#) and [Problems with 'our' M.E. \(or CFS, CFIDS or ME/CFS\) advocacy groups.](#) See also: [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' plus](#) [The misdiagnosis of CFS](#), [Why the disease category of 'CFS' must be abandoned](#) and [Smoke and Mirrors](#)
- For information about the medical similarities, and political differences, between M.E. and MS see [M.E. vs MS: Similarities and differences](#)
- 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.
- For more information on all aspects of M.E. see: [What is Myalgic Encephalomyelitis?](#) and [Testing for M.E.](#)

#### **Relevant quotes by other M.E. advocates:**

'What happened with MS, is NOT going to happen for us now with M.E. MS was hijacked by psychiatrists for their own gain and called 'hysterical paralysis' for many years. This only ended when clear evidence showed that MS was an organic neurological disease. Many M.E. advocates continually compare what happened with MS then to what is happening with M.E. now but it is not at all the same. There are huge differences. Ample evidence M.E. is neurological existed BEFORE the psychiatrists and vested interest groups got involved. The evidence is now overwhelming and still the 'CFS' lies and cover-up persist. If you think that 'more science' will or could get M.E. patients out of this mess, then you aren't aware of even the most basic facts and history on this topic and have mistaken mere propaganda (created by vested interest groups working against our interests) for legitimate and factual information. The facts and history of M.E. and 'CFS' make it very clear that this is entirely a political fight. Refusing to accept this fact only helps the abuse continue.' J.M., M.E. advocate and patient

"Of course we need more research but we do not need to wait for "more science" or the Holy Grail of a marker - even to "prove" that it is "real." NO other illness has been held to this unattainable standard and if we keep buying

into this line of thinking we only hold ourselves back. There is substantial objective, well-documented evidence of CNS, immune, endocrine, cardiovascular, and autonomic nervous system abnormalities, which indicate that it is biologically, not psychologically determined. We need to keep pushing for recognition and utilization of what we have and can use now, not always waiting for more". Jill McLaughlin

Enough of the CFS lies, formerly known as Atypical Poliomyelitis, M.E. experts stated that the epidemics in the 1980s were in fact M.E. as named in 1956 and classified by WHO as a neurological disease in 1969. No to ME/CFS or Myalgic Encephalopathy or the Unfair Name Change Campaign. There is proof of chronic low-grade inflammation in Myalgic Encephalomyelitis, diagnostic tests of the serious pathophysiology do exist but treatments are being unnecessarily delayed. This Polio/AIDS-like disease is a major public health threat that must be urgently addressed by DHHS, NIH and CDC - why are we waiting for treatment and prevention? John Anderson

Can I make a plea for anyone doing an interview or providing information to the media... When you talk about the need for more biomedical research PLEASE be sure to stress that there is ALREADY a significant amount of research proving that ME exists as a discrete well-defined organic disease. We know enough about it to know it affects a wider range of bodily systems than multiple sclerosis for example. We know enough about it to know what systems are more likely affected (muscle, CNS, vascular) and which tests can help confirm diagnosis, guide an monitor management. We even know that some biomedical treatments are available (as per Cheney etc) even if the NHS is extremely reluctant to endorse a non-psychiatric approach, and of course they probably don't get to the root cause as yet.

We are not insisting on biomedical research to "prove that ME is a medical disease". We already KNOW that. The WHO knew that in 1969, the RSM knew that in 1978. There's a whole history of epidemics and some deaths dating back decades. Pellew and Miles transferred the infection to monkeys in the 1950s, one of which died from heart failure, and the post mortem showed "disseminated lesions scattered throughout the nervous system from the brain to peripheral nerves and associated with perivascular round cell infiltration" (Parish, 1978). There are now [many hundreds of] published papers confirming organic disease, despite the mess of confusion of ME with vaguely defined fatigue syndromes. Many of the old papers can be found on the MERUK web site, some in full, and Pubmed has abstracts of recent studies.

Arguing that we need to "prove" ME is playing into the psychs' hands in appearing to agree we have nothing but a belief and no evidence, and so can't with confidence confirm the psychs are wrong. Which couldn't be further from the truth.

The primary needs of research are for treatments, further delineating the etiology and for better diagnosis. Only biomedical treatment offers the practicality to counteract CBT/GET. The cause of multiple sclerosis is hotly debated (virus, vitamin deficiency, genetic?) yet it doesn't have the clear historical pathogenic associations that ME has.

It's really important for listeners/readers to get the message that ME is NOT an "enigma" or a "mystery", it's not a "belief system", "unexplained", "biopsychosocial", "difficult to define", nor a "diagnosis of exclusion" and DOES have objective signs. It's what it says on the box, a serious multisystem disease (the people who say otherwise have no place meddling in areas beyond their expertise), albeit one that needs much more medical attention and less glib, patronising Orwellian dishonesty.

The reasons why so many professionals appear not to know about the disease is not lack of research, it's political, with the data being censored by the dominant UK CBT hegemony. Of course, biomedical research is needed anyway, but the psychiatric empire is so powerful that it's unlikely biomedical research alone could break through without political pressure as well.

(I also think GPs would feel less helpless if they knew it was possible to take a pro-active biomedical approach in investigating and using such treatments extant e.g. mitochondrial, antioxidant, neurological -- some of which \*are\* as safe as food -- rather than dispensing antidepressants as if they pay a commission.) Mike (last name supplied), M.E. patient and advocate

Far too many Drs, researchers and even (often self-claimed) experts are continuing to lump ME, a neurogenic illness classified by the WHO under G93.3, with 'CFS' (Fukada, et al), which is based on 'fatigue' and is referred to as 'ill-defined', etc. Understanding the significant differences is not difficult, when one is familiar with ME and knows what to look for. PLEASE do all that you can to rectify this untenable situation!! Please share this information--and all that I have previously sent you--with others and implement a workable plan, collaboratively. Too many years have been wasted already...too many lives already lost. YOU can do this, if you just decide to. LK Woodruff, M.E. advocate

It is becoming rare to see anyone speak the truth about ME and the capitulation of former ME advocates to the fatal ruse of conjunctive terms (and mixed definition) is happening far too often. M. Beck, M.E. advocate

Modern technology has now served to confirm and to detail the meticulous clinical and scientific observations made about ME before 1988! We can rest assured that this serious disability can arise (like polio) from an initially trivial infection which has epidemic and pandemic potential but we need to give further thought to any name change. We should, instead, be making maximum use of modern and effective means of diagnosis, prevention and management. Dr Elizabeth Dowsett (on the use of the term 'Myalgic Encephalopathy')

'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. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance. 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.' Dr Byron Hyde 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

The current confusion over the name in the US is that CFS, the fabricated condition that somehow became officially synonymous with the real disease Myalgic Encephalomyelitis, is to be cunningly renamed Myalgic Encephalopathy. The problem is that both names share the initials ME, and since Myalgic Encephalopathy will retain the terribly misleading CFS criteria this name is nothing more than a clever diversion to draw our attention away from the real issues. John Anderson, M.E. advocate

To the very few physicians still practicing today who began seeing patients with this illness some 40 years ago and who have continued to record and publish their clinical findings throughout, the current enthusiasm for renaming and reassigning this serious disability to subgroups of putative and vague "fatigue" entities, must appear more of a marketing exercise than a rational basis for essential international research. It was not always so unnecessarily complicated! Dr Elizabeth Dowsett

There is no such disease(s) as CFS. There are actually 30 well documented causes of 'chronic fatigue'. To say that ME is a 'subset' of CFS is just as ridiculous as to say it is a 'subset' of diabetes or Japanese B encephalitis or one of the manifestly absurd psychiatric diagnosis, such as, 'personality disorder' or 'somatisation'.

ME 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 (The brain can no longer receive, store or act upon information which enables it to control vital body functions, cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance, appreciation of space, shape etc). It has an UNIQUE Neuro-hormonal profile.

The problem we face is that, in spite of overwhelming epidemiological and technical evidence of an infectious case, the truth is being suppressed the government and the 'official' ME charities as 'too scary' for the general public .

Infections follow predictable courses, they can easily be diagnosed, managed and prevented. Having worked with them for some 50 years I have seen the results of cover up, drug company pressure, research rivalry and ultimate disaster - all of which could have been prevented. Meantime research workers (such as Richard Lacey who warned about BSE, Listeria, Salmonella etc) get the sack and lose all research findings. Differences between ME & CFS by 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 Gilliam, in his analysis of the Los Angeles County General Hospital M.E. epidemic in 1934, called M.E. atypical poliomyelitis. Dr Byron Hyde

Under epidemic and primary M.E. there is no consensus as to the viral or infectious cause. Much of this lack of consensus may be due to the non-separation of acute onset from gradual onset patients. Primary M.E. is always an acute onset illness. Doctors A. Gilliam, A. Melvin Ramsay and Elizabeth Dowsett, John Richardson of Newcastle-upon-Tyne, W.H. Lyle, Elizabeth Bell of Ruckhill Hospital, James Mowbray of St Mary's and Peter Behan all believed that the majority of primary M.E. patients fell ill following exposure to an enterovirus (Poliovirus, ECHO, Coxsackie and the numbered viruses are the significant viruses in this group). I share this belief. In my tests in Ruckhill Hospital in Glasgow, I found confirmation of enteroviral infection only in acute onset patients and not in any gradual onset [ie. CFS] patients. Dr Byron Hyde

With the rapid development of technology and access to international publication, the UK retained its reputation as a leading centre of M.E. research and remained able to report clinical studies backed up by molecular biology, brain imaging, sophisticated hormonal and other biochemical studies. At this point, with sound evidence of an infective cause, the way in which such infection is spread and the pathogenesis of the disease, why were we urged to adopt the "fatigue definitions" inflicted upon M.E. sufferers by USA scientists? Dr Elizabeth Dowsett

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

Myalgic encephalomyelitis is a common disability but frequently misinterpreted. Amongst 6,000 patients referred for general microbiological diagnosis between 1975 and 1987, 420 cases were recognized. This illness is distinguished from a variety of other post-viral states by a unique clinical and epidemiological pattern characteristic of enteroviral infection. Prompt recognition and advice to avoid over-exertion is mandatory. Dr Dowsett and Dr Ramsay

'The physician and patient alike should remember that CFS is not a disease. It is a chronic fatigue state. The one essential characteristic of M.E. is acquired Central Nervous System (CNS) dysfunction, that of CFS is primarily chronic fatigue.' Dr Byron Hyde

Read more quotes at: [www.hfme.org](http://www.hfme.org)

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

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