

The myths about M.E.

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Because of the vast amount of inaccurate information being propagated about Myalgic Encephalomyelitis by various vested interest groups (helped immeasurably by the creation of the bogus disease category of ‘CFS’ in the 1980s as well as a number of vague and misleading umbrella terms such as ‘ME/CFS,’ ‘CFS/ME,’ ‘PVFS,’ ‘ME-CFS,’ ‘CFIDS’ and Myalgic ‘Encephalopathy’ etc.) it is important to explain briefly what are the myths about M.E., and the facts of M.E.

There are so many myths about Myalgic Encephalomyelitis and many of them are so widespread that it is not uncommon to read articles in the media composed ENTIRELY of such material. Articles which do not contain even one legitimate fact about the illness! Despite popular opinion however, there is an *abundance* of scientifically accurate information about M.E. that is freely available. It spans over 70 years and has been featured in prestigious peer reviewed medical journals all over the world. Tragically however, this information keeps being blocked at every stage by the unscientific myths and propaganda created by vested interest groups. It is a victory of vested political and financial interests over ethics, science, logic, patient welfare, and REALITY.

What follows is a list of some of the most common myths about M.E.:

1. MYTH: M.E. is a new illness that appeared for the first time in the 1980s
2. MYTH: M.E. does not occur in outbreaks or epidemics
3. MYTH: M.E. is an illness whose primary and defining feature is ‘chronic fatigue.’
4. MYTH: Myalgic Encephalomyelitis and ‘CFS’ are synonymous terms
5. MYTH: People suffering with chronic fatigue have mild M.E.

6. MYTH: All studies or articles which use the terms CFS (or ME/CFS, CFS/ME, CFIDS or Myalgic Encephalopathy) are discussing the same patient group
7. MYTH: The 8 symptoms – along with fatigue – listed in the CDC’s 1994 Fukuda CFS diagnostic criteria (short-term memory or concentration problems, sore throat, tender cervical or axillary lymph nodes, multi-joint pain, muscle pain, headaches, non-refreshing sleep and/or post-exertional malaise) are the symptoms which define M.E. Fitting the Fukuda criteria for CFS, or any of the other CFS definitions, means that a person has Myalgic Encephalomyelitis
8. MYTH: Fibromyalgia and M.E. are basically (or exactly) the same illness: fatigue is the worst symptom of M.E. and in Fibromyalgia the worst symptom is always pain and that's really the only way you can tell which one you have. M.E. is also basically (or exactly) the same illness as Lyme disease, Multiple Chemical Sensitivity Syndrome and Gulf War Syndrome etc.
9. MYTH: M.E. is a mild illness from which every person will eventually completely recover and is never progressive or fatal
10. MYTH: M.E. has been scientifically proven to be caused by psychological factors. M.E. is a 'mysterious' illness with many 'medically unexplained' symptoms and seems to ‘transcend the boundaries between the body and the mind’ like no other. No research exists which shows that M.E. has a physical or organic basis
11. MYTH: M.E. is consequent from an organic (viral) trigger but the illness is short lived unless there are psychological and social factors which perpetuate the illness long term
12. MYTH: It is only recently that researchers have finally shown that M.E. has a physical or organic basis
13. MYTH: Only very mild abnormalities have ever been found in M.E. patients
14. MYTH: The only treatments shown to be useful in treating M.E. are CBT (cognitive behavioural therapy) and GET (graded exercise therapy). CBT/GET treatments are useful in 'rehabilitating' M.E. sufferers because M.E. is perpetuated by deconditioning and inactivity. These treatments are

also completely safe and there is no risk associated with them for M.E. patients

15. MYTH: All laboratory tests will always come back normal in M.E. patients and so there are no tests that can be done which can confirm a suspected M.E. diagnosis. Diagnosis is extremely difficult
16. MYTH: M.E. is only a diagnosis of exclusion, a wastebasket diagnosis. It is not a distinct disease.
17. MYTH: M.E. can not be diagnosed until after 6 months have passed, M.E. is a gradual onset illness
18. MYTH: There are never any observable physical signs of illness in M.E.
19. MYTH: The symptoms and severity level of the illness remains constant in M.E. If a patient can do something once, they can obviously do it many times; if a patient can do something on one day, of course they will also be able to do it the next day too, or on any other day.
20. MYTH: Research into M.E. is well funded by government
21. MYTH: M.E. primarily or only affects white, affluent and well-educated women
22. MYTH: There are no children who have M.E.
23. MYTH: Most people (or everyone) with M.E. has a 'type A' or perfectionist personality and this has caused or perpetuated the illness
24. MYTH: M.E. can result from becoming run down physically or is the end result of high levels of stress, long term stress or childhood trauma or abuse
25. MYTH: M.E. can be caused by the Epstein-Barr virus, glandular fever/mononucleosis, Q fever, HHV6 or Ross River virus
26. MYTH: Evidence exists which suggests or shows that M.E. is caused (partially or completely) by XMRV infection, and this theory fits all the major facts of M.E. (with no big 'holes')
27. MYTH: The recent XMRV 'CFS' research was conducted on a distinct and 100% M.E. patient group. This research clearly separates M.E. patients

from those with 'CFS.'

28. MYTH: The recent XMRV 'CFS' research shows promise in providing a unique test for M.E.
29. MYTH: Evidence exists which suggests or shows that anti-retroviral treatments (perhaps specific to XMRV) are the treatment breakthrough that M.E. patients have been waiting for, for so long. This type of treatment represents real hope (or certainty) of a cure for M.E. patients.
30. MYTH: XMRV is believed to be an important and absolutely vital scientific lead to follow, by all of the M.E. community.
31. MYTH: The term Myalgic Encephalopathy is more medically accurate than the term Myalgic Encephalomyelitis and so using the term Myalgic Encephalopathy is in the best interests of authentic M.E. sufferers
32. MYTH: All those advocacy organisations (and individuals) which publicly state that M.E. (or ME/CFS, CFS/ME or CFIDS etc.) is not 'all in your head' are trustworthy and are working for the benefit all M.E. sufferers and are a good source of information about Myalgic Encephalomyelitis.
33. MYTH: All those who state publicly that they believe M.E. to be a purely psychological or behavioural illness are basing their stance on a comprehensive and unbiased examination of the medical evidence and actually believe what they are saying. There is a legitimate scientific debate about whether or not M.E. is 'real' or if it is psychological or neurological.
34. MYTH: The name CFS was chosen in 1988 by a group of experienced M.E. clinicians who thought it was the most medically accurate name for the illness at that time
35. MYTH: It is the name CFS itself that is the cause of all the misunderstandings about the illness. If the name Myalgic Encephalomyelitis was renewed (for example) patients would automatically start to get the recognition and respect they deserve, more money for legitimate research and everything else they so desperately need
36. MYTH: Once we have enough hard science behind M.E. – in particular a single diagnostic marker for the illness – things will improve for M.E. sufferers and M.E. will automatically start to get the medical recognition and respect it deserves. (The problem is only that we lack enough science.)

The truth is that every one of those statements is completely untrue despite how often they have been repeated to us and presented as ‘facts.’

To the M.E. patients reading this: were you surprised by some of them? The sad truth is that it isn't just the general public that have been lied to repeatedly about almost every aspect of this illness; but every M.E. sufferer as well. The consequences of that for people with the illness, as we all well know, have been devastating. As Hillary Johnson, author of 'Osler's Web' (a book which exposed the truth behind the US 1980s M.E. epidemics) writes:

There is no one individual who is going to fly in with a velvet cape on their back and save the day. Only the patients can, but it's going to take guts. When they start to demonstrate some guts, it's my guess that the researchers you so want to support you will line up one by one and start supporting you over time. Some kind of critical mass must be achieved, until there are more people standing on one side than the other, and the lie starts to crumble and the perpetrators will skitter away to higher ground.

It is not a matter of if M.E. sufferers will win the battle for formal recognition and fair treatment but of when; when is entirely up to M.E. patients and how hard we are willing to fight. (Sadly nobody else seems at all willing to do any of the fighting for us. Despite having science and REALITY on our side, as well as ethics, we have been abandoned by the media, most doctors and scientists, our governments and even human rights groups, thus far at least.)

The onus is also on those in the media, doctors, lawyers and the general public to educate themselves about the facts of M.E.; to stop perpetuating myths about the illness and to do what they can to stop the needless neglect and abuse of some of the most vulnerable members of our society. The media in particular (with some notable exceptions) has really not served people with M.E. well over the last 20 years. As was stated in the introduction, it is still very common to read articles in the media composed ENTIRELY of this unscientific propaganda. The media plays a significant role in perpetuating the serious abuse M.E. patients are subjected to.

Sources of M.E. information on this site which debunk all the myths listed above in more detail (and which are each fully referenced) include:

1. [What is M.E.? A medical and political overview](#)
2. [Who benefits from 'CFS' and 'ME/CFS'?](#)
3. [The misdiagnosis of CFS](#)
4. [Myalgic Encephalomyelitis is not fatigue, or 'CFS'](#)
5. [Smoke and mirrors](#)

6. [Putting research and articles on M.E. into context](#)
7. [Testing for Myalgic Encephalomyelitis](#)
8. [Why the disease category of 'CFS' must be abandoned](#)
9. [Problems with 'our' M.E. \(or CFS, CFIDS or ME/CFS\) advocacy groups](#)
10. [The effects of CBT and GET on patients with Myalgic Encephalomyelitis](#)
11. [The ultra-comprehensive Myalgic Encephalomyelitis symptom list.](#)

See also: [Myalgic Encephalomyelitis research and articles.](#) This is a collection of literally HUNDREDS of some of the best M.E. research and articles, from some of the worlds leading researchers, doctors and M.E. advocates. Sections include: M.E. outbreaks, M.E. and children, viral research, cardiac research, the severity of M.E. and many more. Please read [Putting research and articles on M.E. into context](#) and [A warning on 'CFS' and 'ME/CFS' research and advocacy](#) first however.

To read a complete list of the articles and resources available on the site suitable for different groups – severe M.E. patients, M.E. patients, patients misdiagnosed with 'CFS,' doctors, the media, friends and family of M.E. patients, carers and so on – see the new [Information Guides](#) page.

The problem here is *not* a lack of scientific evidence, but that the evidence which exists is continually ignored by many of those in positions of power who are abusing that power to further their own vested interests. This pretence of ignorance on behalf of Governments (and others) has had devastating consequences for people with M.E. and has also meant that the number of M.E. sufferers continues to rise unabated. The decades of systemic abuse and neglect of the million or more people with M.E. worldwide has to stop.

Will it take another 20 years? How much more extreme does the suffering have to be? How many more hundreds of thousands of children and adults worldwide have to be affected? How many more patients will have to die needlessly or be horrifically abused or neglected before something is finally done? How many more patients have to be left at home to die alone, without even the support or respect of their families?

People with M.E. have only a tiny minority of the medical, scientific, legal and other potentially supporting professions – or the public – on their side. What is needed is for 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 refuse to accept anything less than the facts about M.E. and encourage others to do the same. Knowledge is power.

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. (and those misdiagnosed with ‘CFS’ who do not have M.E.) desperately need your help.

The ‘CFS’ scam is tissue thin and M.E. is a serious and potentially fatal distinct neurological disease. These facts are very easily discovered if one merely takes a small amount of time to look at the actual evidence.

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: see What is M.E.?

The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and ‘CFS’ and ‘chronic fatigue’ are very

different and distinct, and it is the definitions of each of these terms that is of primary importance. In summary:

- **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.
- **Myalgic Encephalomyelitis** is a distinct disease. It has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disease with the code G93.3. Myalgic Encephalomyelitis is a systemic acutely acquired illness initiated by a virus infection which is characterised by 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) which results in dysfunctions and damage to many of the body's vital 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. is primarily neurological, but symptoms may also be manifested by cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. More than 64 distinct symptoms have been authentically documented in M.E., several of which are unique to the disease. 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.

M.E. can occur in both epidemic and sporadic forms and over 60 outbreaks of the illness have been recorded worldwide since 1934. M.E. can be extremely disabling and in some cases the illness is fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

‘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 Malcolm Hooper 2003

‘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’ 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

‘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

Increasingly, it is now "policy-makers" and Government advisers, not experienced clinicians, who determine how a disorder is classified and managed in the NHS: the determination of an illness classification and the provision of policy-driven "management" is a very profitable business. To the detriment of the sick, the deciding factor governing policies on medical research and on the management and treatment of patients is increasingly determined not by medical need but by economic considerations. Given that what Wessely promotes is contrary to the established scientific evidence, how does he manage to maintain such power and control? The implementation of his personal philosophy is not based on medical science and has had devastating consequences, not just for sufferers of M.E. but for their families as well. There is a gross mismatch between the severity and complexity of M.E. and the medical and public perception of the disorder, but until Simon Wessely is held to public account, and medical professionals and public alike are informed and educated about the reality of M.E., this will continue. Professor Malcolm Hooper

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

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

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

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- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were ‘atypical multiple sclerosis’ and ‘atypical polio.’
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation’s International Classification of Diseases since 1969 as a distinct organic neurological disease.
- 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 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 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.