

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.

Avoiding overexertion in M.E. - Summary

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The single biggest factor determining recovery and remission from Myalgic Encephalomyelitis (M.E.) at this point is undoubtedly appropriate rest in the early and/or severe stages of the illness. The importance of avoiding overexertion in M.E. **can not** be overestimated.

M.E. patients that are newly diagnosed, or still in the acute stages especially must be given their best possible chance for recovery and be enabled to REST appropriately. Improvements in symptoms and stability of the illness can also be positively affected at every stage of the illness by appropriate activity management/reduction. Limiting activity levels to only as much as the patient is capable of dealing with may well be the single most important factor in the patient's M.E. improving over time.

It is vital that patients avoid physical over-exertion and are never encouraged to exercise (or be active) beyond their individual limits particularly in the early and acute stages of the illness, but also at *any* stage of the illness. There is nothing to ever be gained by people with M.E. pushing themselves beyond their limits physically as this can *only* cause unnecessary relapses. Permanent damage (eg. to the heart) and disease progression may also be caused and there have also been reports of sudden deaths in M.E. patients following exercise.

Avoiding overexertion doesn't guarantee a quick recovery or any recovery at all, there are other factors at work too, but overdoing it physically is a sure way to ensure that the patient remains more severely ill and for longer than would otherwise have been the case.

For those with M.E., resting as much as is needed is not just 'doing nothing' - it is an active and vital disease management process.

- **Note:** For the very severely ill there will be no safe or symptom-free activity limit and concepts of stopping activities before damage is done are useless unfortunately and indeed a sizeable proportion of the very severely ill may well be so severely affected in the first place BECAUSE of overexertion in the early stages of their illness. This guide is aimed primarily at those who are less severely affected (because the very severely affected do not have a 'safe' activity level and must always limit activities as much as possible).

What is Myalgic Encephalomyelitis? What characterises M.E. every bit as much as the individual symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. The way the bodies of people with M.E. react to these activities/stimuli post-illness is unique in a number of ways. Along with a specific type of damage to the brain, this characteristic is one of the defining features of the illness which must be present for a correct diagnosis of M.E. to be made. The main characteristics of the pattern of symptom exacerbations, relapses and disease progression (and so on) in M.E. include:

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

- J. Repeated overexertion can harm the patient's chances for future improvement in M.E. M.E. patients who are able to avoid overexertion have repeatedly been shown to have the most positive long-term prognosis.
- K. Not every M.E. sufferer has 'safe' activity limits within which they will not exacerbate their illness; this is not the case for the very severely affected.

This is not simply theory, but is based upon an enormous body of clinical information and mutually supportive research. Confirmation of this hypothesis is supported by electrical tests of muscle and brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. M.E. is neither 'mysterious' nor 'medically unexplained'.

Research and articles on this topic An abundance of research and articles support the importance of avoiding overexertion in Myalgic Encephalomyelitis. To read more articles see the [full-length version of this text](#).

MYALGIC ENCEPHALOMYELITIS By A. Melvin Ramsay M.D., Hon Consultant Physician, Infectious Diseases Dept, Royal Free Hospital. [Published 1986] 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.** Those who are given complete rest from the onset do well and this was illustrated by the aforementioned three patients admitted to hospital in an unconscious state; all three recovered completely. Those whose circumstances make adequate rest periods impossible are at a distinct disadvantage, but no effort should be spared to give them the all-essential basis for successful treatment. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.

Theres no smoke without fire! Some comments on the tendency to relapse in ME by Dr Elizabeth Dowsett
WHAT IS A RELAPSE? It is an unexpected deterioration in the condition of a sick person after partial recovery. The commonest causes of such a reverse in ME appear to be mental and physical over exertion.

SEVERELY AFFECTED ME (MYALGIC ENCEPHALOMYELITIS) ANALYSIS REPORT ON QUESTIONNAIRE (Word document) ISSUED JANUARY 2004. **Results of survey:** Graded exercise therapy: 95% found it unhelpful. Cognitive behavioural therapy: 93% found it unhelpful

Patient accounts of graded exercise therapy (GET) GET is a specific type of exercise program often forced on M.E. patients due to studies which have shown benefit with it on 'fatigued' people who do NOT have M.E.. To read more patient accounts see: [Section 6](#) of the CBT and GET database and the [Case Studies](#) section.

- Ruth. 'I have been severely affected by M.E. for the past 14 years, completely bed bound for about 10 of those years, and had between 5% and 10% of my former health for the other 4. When I read headlines saying that an exercise regime was the answer to my ill health I couldn't understand it, as every time I tried to push myself physically even in small incremental steps I would deteriorate significantly. The last time I was able to walk I managed to convince myself that I was heading for a full recovery, and so increased my activity regardless of whether I was able for it, the result of this is that I have been unable to get out of bed for the past 6 1/2 years.'
- Annette. 'I have done 2 GE programs under supervision. They both left me far worse off than before for a long period. The symptoms got much worse (sore throat, sinus infections, weakness, fainting) grew progressively worse and I had to abandon the exercise. The first one was early on in my illness (ME as per Ramsay) and probably led to the illness becoming permanent.'

M.E. patients that are newly diagnosed, or still in the acute stages especially must be given their best possible chance for recovery and be enabled to REST appropriately. Improvements in symptoms and stability of the illness can also be positively affected at every stage of the illness by appropriate activity management/reduction.

- See the [Full-length version of this text](#) and [The effects of CBT and GET on patients with M.E.](#) for more information on the negative effects of exercise on M.E. patients, and for references.
- See [Who benefits from 'CFS' and 'ME/CFS'?](#), [Smoke and Mirrors](#) and [Why the disease category of 'CFS' must be abandoned](#) for a discussion of why the disease category 'CFS' must be abandoned and why renaming or sub-grouping 'CFS' cannot work.
- See [What is M.E.?](#) for more information on all aspects of M.E.

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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 purely 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 the full-length text or the [References](#) page for a reference list.

“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

‘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 2006

Dr Melvin Ramsay on Myalgic Encephalomyelitis: *“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.”*

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

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

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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 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.