

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.

The importance of avoiding overexertion in M.E.

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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 (partial) recovery or any recovery at all, there are other factors at work too, but overexertion 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.

What is meant exactly by the term 'resting?'

Resting means completely different things at different severity levels of illness. For the mildly ill resting may mean watching TV or perhaps sitting in a chair reading a book or having a quiet night in with friends. For the severely ill, these activities are not at all restful and indeed would provoke severe relapses.

For the very severely ill, resting means lying down in a dark room, in silence and with no sensory input at all (such as TV or radio or light) and not moving at all physically or engaging in any type of cognitive activity. Clothing must also be comfortable and the room must be neither too warm nor too cold. For the very severely ill a better term would be 'complete incapacitation,' rather than 'resting.' The term 'resting' implies that the inactivity is optional and this is often not the case in the severely ill who are often 'resting' (i.e. incapacitated) because it is physically impossible for them to do anything else.

For moderately ill patients resting means something somewhere between the two extremes, and so on.

Of course for the very severely ill there will be no safe or symptom-free activity limit. Concepts of pacing or of keeping activity at a level which does not cause immediate or delayed symptoms are useless. 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, because they were not told how important it was to rest or were not allowed to rest adequately. This is extremely common in M.E. It is a tragedy and an absolute disgrace.

Note that I have never heard of anyone with M.E. who is *too* restrictive with their activity levels; the problem is always the opposite, if anything. It is human nature to want to do things and to want to live and experience life as much as possible. It is very difficult for the person with M.E. to be unable to do so many things and it requires enormous discipline to avoid overexertion. Severe M.E. restricts life to a degree that healthy people might find hard to imagine, but patients have learnt from bitter experience many times over the extreme negative consequences of overexertion. Patients are reminded of this every week if not every day as even with careful control, limits can be misjudged or tasks can take a greater toll than expected.

For most if not all patients it is much harder to rest adequately than it is to keep pushing yourself to do things even to the point of worsening the illness. It is often much easier to just keep doing things and suffer the dire consequences in the short- and long-term, rather than stand up to extreme pressure from friends, family and medical staff for these activities to be completed as they were before the patient's illness, unfortunately.

Resting so endlessly for many years on end is much harder than you can imagine. (It has been commented many times that learning to walk again, or speak again after a stroke or accident would be so much easier than having to just rest endlessly and do almost nothing and to have no distraction from the extreme pain. People with M.E. would give anything to be able to work hard to improve their illness, and to be improving every day instead of staying the same or getting worse.) The problem of M.E. patients under-reporting or underestimating their ability levels just does not exist.

This is not about patients being as inactive as possible. Of course a person with moderate M.E. of course does not need to live with the same restrictions as does someone with severe M.E. The point here is just that patients must stay within their individual post-illness limits. No more and no less than that is necessary.

Increasing the activity levels of someone with M.E. beyond their individual limits can only ever be harmful. It really doesn't matter if this is done gradually or all at once.

The evidence which shows that some 'CFS' patients are merely deconditioned and can be restored to health through graded exercise programs is based on patients who DO NOT have M.E. None of the various cardiac, cardiovascular, immunological, neurological, cognitive, muscular, and other abnormalities present in M.E. sufferers – which together cause the high level of disability associated with M.E. – can be explained by mere 'deconditioning.' *Patients who improve with graded activity programs do not have M.E.* It should go without saying that treatment of one disease cannot be determined by studying a completely different and unrelated (and mixed) patient group. Yet this essential medical and logical guideline is all too often ignored when it comes to M.E. unfortunately. In this case, money speaks louder than logic, science or ethics. Please don't fall for this nonsense about 'deconditioning' or about 'CFS' supposedly being just another term for M.E. and so on. It has nothing to do with M.E. For more see: [Smoke and Mirrors](#). To summarise:

- No one with M.E. is *too* restrictive with their activity levels and M.E. patients do not underestimate their activity levels
- It is very difficult for M.E. patients to restrict their activity levels, and requires a high level of discipline
- M.E. patients know from bitter experience the negative consequences of overexertion
- The appropriate activity level depends of the severity of each patient's illness
- The symptoms of M.E. are not caused by deconditioning
- Graded exercise does not help M.E.; if a patient improves with graded activity, they do not suffer from M.E.
- Some patients that qualify for a 'CFS' diagnosis may improve with graded exercise, but these patients do not suffer from M.E.

What is Myalgic Encephalomyelitis?

Myalgic Encephalomyelitis (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. It can occur in both epidemic and sporadic forms, over 60 outbreaks of M.E. have been recorded worldwide since 1934.

What defines M.E. is a specific type of damage to the brain. Myalgic encephalomyelitis is an acutely acquired illness initiated by a virus infection with multi system involvement which is characterised by post encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name 'Myalgic Encephalomyelitis'). Central nervous system (CNS) dysfunction, and in particular, inconsistent CNS function is undoubtedly both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process. Myalgic Encephalomyelitis also causes a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits.

M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. Again, although M.E. is primarily neurological it is also known that the vascular and cardiac dysfunctions seen in M.E. are also the cause of many of the symptoms and much of the disability associated with M.E. – and that the well-documented mitochondrial abnormalities present in M.E. significantly contribute to both of these pathologies.

There is also multi-system involvement of cardiac and skeletal muscle, liver, lymphoid and endocrine organs in M.E. Some individuals also have damage to skeletal and heart muscle. Thus Myalgic Encephalomyelitis symptoms are manifested by virtually all bodily systems including: cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage.

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) – and an associated injury of the immune system – by the chronic effects of a viral infection. There is also transient

and/or permanent damage to many other organs and bodily systems (and so on) in M.E. M.E. affects the body systemically.

What characterises M.E. every bit as much as the individual symptoms however 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 (the CNS) 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'.

M.E. affects all races and socio-economic groups and has been diagnosed all over the world with a similar strike rate to multiple sclerosis. Children as young as five can get M.E., as well as adults of all ages. M.E. is similar in a number of significant ways to illnesses such as multiple sclerosis, Lupus and Polio. 25% of M.E. sufferers are severely affected and housebound and/or bedbound. In some cases Myalgic Encephalomyelitis can also be progressive, or fatal. M.E. is an infectious neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of unexplained 'fatigue.'

- See [The M.E. Symptom List](#) for references and for more detailed information.
- See [The misdiagnosis of CFS](#) for information on some of the illnesses which are commonly misdiagnosed as 'CFS' and what a diagnosis of 'CFS' based on any of the CFS definitions actually means.
- 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 the lack of evidence (and financial and political motivations) behind the 'behavioural' model of M.E. and why the bogus disease category of 'CFS' must be abandoned.
- See [M.E. is not defined by 'fatigue' and Myalgic Encephalomyelitis is not fatigue, or 'CFS'](#) for more information on why 'fatigue' does not define M.E.
- A significant number of the world's leading M.E. experts believe that M.E., like Polio, is caused by an enterovirus, and the evidence which exists to support this theory is compelling. See: [The outbreaks \(and infectious nature\) of M.E.](#) and for more information.
- What is [Homeostasis?](#) Homeostasis is the property of a living organism, to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits.

Research and articles on this topic

An abundance of research and articles support the importance of avoiding overexertion in Myalgic Encephalomyelitis. A small collection of sample articles is reproduced below.

For more information on this topic see:

- [The effects of CBT and GET on patients with Myalgic Encephalomyelitis](#) This paper looks at the physical effects of CBT (psychotherapy) and GET (exercise) on patients with M.E.
- See the paper [Smoke and Mirrors](#) for information on why patients with M.E. are being treated based on theories (such as CBT and GET) motivated by financial and political considerations as opposed to the available medical evidence. This text forms the introduction to a 100 page + [CBT and GET database](#). The database contains excerpts and links to literally hundreds of articles and research studies which expose the lack of scientific legitimacy (and the hidden financial and political motivations) underlying the 'behavioural' paradigm of M.E. and the use of CBT and GET on M.E. patients – as well as a large number of patient accounts of CBT and GET.
- For more articles on this topic see: [General Research and Articles](#), [Cardiac and Cardiovascular Research](#), [Exercise Research](#), [Metabolic research](#), and [Muscle Research](#), and [Research and articles which expose the lack of scientific legitimacy \(and the hidden financial and political motivations\) underlying the 'behavioural' paradigm of M.E. and the use of CBT and GET \(graded exercise therapy\) on M.E. patients.](#)

MYALGIC ENCEPHALOMYELITIS : A Baffling Syndrome With a Tragic Aftermath. By A. Melvin Ramsay, 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.**

Myalgic encephalomyelitis--a persistent enteroviral infection? Dowsett EG, Ramsay AM, McCartney RA, Bell EJ. Basildon Hospital, Essex, UK. 1990 [edited for brevity]

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.

The book: **The Clinical and Scientific Basis of Myalgic Encephalomyelitis** edited by Dr Byron Hyde

Dr Byron Hyde in his [M.E. textbook](#), explains that it has been found that those patients with M.E. who returned to work soon after becoming ill or while they were still seriously or severely ill – instead of having an extended period of rest and recovery – are at risk of causing an abnormal increase in damage ‘to a heart muscle already vulnerable and under attack from an acute viral infection.’ He also writes that:

This is not just clinical supposition, there is a strong basis for this belief of work or exercise potentiated heart damage in the literature. It is well known that enteroviruses may cause chronic cardiac disease as well as major neurological injury. Kandolf states that “enteroviruses are capable of causing dilated cardiomyopathy of sudden onset or lead to a variety of common arrhythmias.” Utilizing mouse models, Wilson and again Reyes demonstrated that Coxsackie infected [enterovirus infected] mice, forced to swim to the point of exhaustion during the acute phase of infection, developed chronic heart disease whereas Coxsackie infected mice who were allowed to rest during the acute phase, did not develop chronic heart disease.

M.E. represents a possibility of serious cardiac injury primarily in patients who exercise or maintain exhaustive work efforts during the onset of their illness. It is possible that some of these patients who die and others that develop major cardiac changes are never recognised as M.E.

Those who do not, or cannot, rest in the early stages of M.E. potentially create, says Dr Hyde, ‘a physical injury to the myocardium, cardiac pacemaker cells or their autonomic control,’

M.E. is an infectious neurological disease and represents a major attack on the central nervous system (CNS) by the chronic effects of a viral infection. A significant number of the world’s leading M.E. experts believe that M.E., like poliomyelitis, is caused by an enterovirus. Dr Hyde explain that enterovirus infections are able to cause:

- a. a chronic host infection
- b. major or no cardiac disease depending on the virulence of the subtype
- c. cardiac injury dependent upon the sex of the patient and of the level of physical activity of the patient during the acute or infectious stage
- d. cardiac disease depending upon the immunological variability of the host.

An enterovirus would also explain the; age variation, sex variation, obvious resistance of some family members to the infection and the effect of physical activity (particularly in the early stages of the illness) in creating more long-term/severe M.E. illness in the host.

Dr Hyde also writes that;

With both CNS and CVS disease, chronicity may be provoked by maintaining strenuous exercise and work levels during the acute and recovery stage of the viral illness. Early patient activation may represent serious cardiovascular danger to patients [with M.E.]. The strange concept of waiting 6 months to diagnose a classical case of M.E. is unnecessary and fraught with potential danger to the patient. Such a diagnostic delay may create legal consequences for the physician. Physicians who take an early aggressive approach in physically activating these acute stage patients may do so at both their and their patient’s peril.’

From 'The Myalgic Encephalomyelitis symptom list' on this site:

‘Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is very common – if not universal – in Myalgic Encephalomyelitis. (Although a small percentage of sufferers may possibly be somewhat less severely affected at onset.) This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change. The onset of M.E. is frequently very dramatic, M.E. patients can very often tell you not just the day that they became ill, but the exact *hour* they became ill.’

‘The types of symptoms produced in response to certain levels of physical activity, cognitive activity, sensory stimuli or orthostatic stress may or may not vary depending on the type (and severity) of the activity or stimuli involved. But very often the types of symptoms worsened or produced by overexertion are fairly similar regardless of which exertion or input was involved. Overexertion can sometimes cause just one or two symptoms to worsen (eg. cardiac problems) but often a large cluster of symptoms are worsened. The cluster of symptoms made worse by excessive exertion or stimulus is often very similar from patient to patient, as generally it is a worsening of the most common symptoms of the illness. Patients commonly experience a combination of the following symptoms:

Profound cognitive dysfunctions (and various other neurological disturbances), muscle weakness (or paralysis), burning eye pain or burning skin, subnormal temperature or low-grade fever, sore throat or painful lymph nodes (and/or other signs of inappropriate immune system activation), faintness, weakness or vertigo, loss of co-ordination, dyspnea, an explosion of sensory phenomena (low level seizure activity), cardiac and/or blood pressure disturbances, facial pallor and/or a slack facial expression, widespread severe pain, nausea or feeling as if ‘poisoned,’ feeling cold and shivering one minute and hot and sweating the next, anxiety or even terror (as an organic part of the attack itself rather than as a reaction to it) and hypoglycaemia. Often the patient will feel an urgent need to retreat from all homeostatic pressures. The types of symptoms triggered vary widely from patient to patient, but some combination of these is common. There may also be an accompanying exacerbation of other symptoms. These symptoms often combine to create an indescribable and overwhelming experience of terrible illness that is unique to M.E, and can be profoundly incapacitating. At its most severe, the patient feels as if they are about to die.’

‘Each of the symptoms caused or exacerbated by overexertion can be clearly articulated without difficulty whether they be; seizures, cardiac events, labile blood pressure, tachycardia, shortness of breath, muscle pain, muscle weakness or muscle paralysis, facial paralysis, black outs, flu-like symptoms, nausea, inability to speak or to understand speech, problems with memory, and so on. It makes no scientific or logical sense to subsume these very specific symptoms, and very specific and varied combinations of symptoms, under a vague and inaccurate label of mere ‘fatigue.’ To say that all of these very different and very specific – and in some cases very serious – symptoms can be accurately summarised as being a problem of mere ‘fatigue,’ ‘malaise’ or ‘exhaustion’ is absurd.’

‘A large number of illnesses cause significant fatigue or malaise after activity (for example post-mononucleosis or glandular fever fatigue syndromes, Lyme disease and Fibromyalgia and so on) but what is happening in M.E. is simply not the same; the symptomatology and pathology – and the effect of physical, cognitive and orthostatic overexertion on long-term prognosis – is very different in M.E.’

‘The severity of M.E. is not stable over the course of a day, or even from one hour (or even one minute) to the next: it also isn’t stable from one week or month to the next. This waxing and waning of the severity of the illness can be very unpredictable. The severity of M.E. also waxes and wanes from one minute/hour/day/week etc. due to the acute and delayed effects of overexertion.’

‘Because of the lack of stability in M.E. you simply cannot know a M.E. sufferer’s usual ability level or severity level unless you have observed them over a very long period of time, or actually asked the person detailed questions about what their average daily activity limits, abilities and symptoms are. Just observing someone with M.E. do a certain task should not be taken to mean; (a) that they can necessarily repeat the task anytime soon, (b) that they would have been able to do it at any other time of day, (c) that they can do the same task every hour, day or even every week, or month, or (d) that they won’t be made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task. Most importantly, because the worsening of the illness caused by overexertion very often does not even begin until 48 or more hours afterwards you also can’t tell by looking if a particular activity was so far beyond a M.E. patient’s individual limits that they will end up having made themselves severely or permanently more ill by completing the task.’

‘Another reason that short-term and superficial judgements of ability and disability levels in people with M.E. are ill-advised and often very misleading – and are in fact almost guaranteed to give a falsely more optimistic view of daily ability levels – is because the relapses caused by exertion very often do not appear until 48 or more hours afterward, when the average observer is long gone.’

‘Recent research shows that mitochondrial dysfunction (etc.) leads to diastolic dysfunction and reduced stroke volume/low cardiac output in M.E. – and that certain levels of orthostatic stress and physical and mental activity etc. exacerbate this cardiac insufficiency. Dr Cheney explained recently that because it takes more metabolic energy for the heart to relax and fill with blood than it does for it to squeeze and pump blood, the hearts of people with M.E. don’t fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. (and much of the disability of M.E.) So the tachycardia – fast heart rate – often seen in M.E. in response to orthostatic stress and so on is actually compensating for low stroke volume to help increase cardiac output. The heart doesn’t fill with enough blood before each beat of the heart so it is forced to beat faster to try to make up some of the shortfall, but people with M.E. are still left with reduced cardiac output leaves them very ill and disabled. If this problem is severe enough it can also result in death. As one M.E. advocate explains: ‘Cardiac output is sometimes too low to meet the demands of movement, and any attempt to exert oneself beyond one’s own capacity for cardiac output - that is when demand exceeds cardiac capacity - would indeed result in death. Studies on dogs have shown that when the demands of the body exceed cardiac output by even 1%, the organism dies. M.E. patients [must] reduce demand and reduce their exertion level to stay within the bounds of their low cardiac output to stay alive.’”

From 'Smoke and Mirrors' on this site:

What is the effect of graded exercise therapy (GET) on Myalgic Encephalomyelitis (M.E.) patients?

As (bad) luck would have it, graded exercise programs are probably the single most inappropriate treatment that a M.E. sufferer could be recommended to undertake. This is because one of the unique features of authentic M.E. is exercise intolerance – that patients worsen with even trivial levels of activity or exercise. Exercise or exertion intolerance is one of the many things which separates Myalgic Encephalomyelitis so distinctly from various post-viral fatigue states or other illnesses involving 'chronic fatigue.' People with M.E. do not improve with exercise. They cannot; exercise intolerance is a large and essential part of *what M.E. is*. Veteran M.E. expert Dr Ramsay explained that this unique characteristic: ‘is virtually a sheet-anchor in the diagnosis of Myalgic Encephalomyelitis and without it a diagnosis should not be made.’ (1986, [Online]).

This essential feature of M.E. is characterised by a unique form of paralytic muscle weakness whereby muscles perform normally to begin with but after even a minor degree of physical effort; three, four or five days, or longer, elapse before full muscle power is restored. This affects all muscles including the heart and is very different from mere ‘fatigue.’ (Ramsay 1986, [Online]) (Hyde 2003, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Dowsett 2001, 2000, 1999.b, b [Online])

Doctors who have experience with M.E. (and can tell the difference between authentic M.E. and various unrelated fatigue states) and the leading M.E. experts all concur; exercise can have many harmful effects on patients both in the short- and long-term. The following comments which illustrate this point are provided by some of the world's leading M.E. experts, all of whom have been specialising in M.E. for many years and each of whom has seen literally *thousands* of M.E. patients;

a. Dr Melvin Ramsay a UK doctor who specialised in M.E. for more than thirty years, from the Royal Free Hospital M.E. outbreak of 1955 until his death in 1990, and who is credited with having written some of the most accurate description of the illness to date, explains; 'The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, **those patients who are given a period of enforced rest from the onset have the best prognosis.** 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.' (Ramsay 1986, [Online])

b. Dr. Elizabeth Dowsett, explains: 'There is ample evidence that M.E. is primarily a neurological illness although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion' and 'Prompt recognition and advice to avoid over-exertion is mandatory' and 'The prescription of increasing exercise can only be counter-productive.' She also states that; '**20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.**' (Dowsett & Ramsay et al. 1990) (Dowsett 2000, [Online]) (Dowsett a, [Online])

c. Dr Byron Hyde explains that: 'I have some ME patients with a circulating red blood cell volume less than 50% of expected and a very large number with the range of 60% to 70%. What this test means is that blood is pooling somewhere in the body and that this blood is probably not available for the brain. When blood flow to the heart decreases sufficiently, the organism has an increased risk of death. Accordingly, the human body operates in part with pressoreceptors that protect and maintain heart blood supply. When blood flow decreases, pressoreceptors decrease blood flow to noncardiac organs and shunt blood to the heart to maintain life. This, of course, robs those areas of the body that are not essential for maintaining life and means the brain, muscles, and peripheral circulation are placed in physiological difficulty.' This physiological difficulty is exacerbated by physical and mental activity and orthostatic stress. Dr Byron Hyde goes on to say that: '**In MRI spectography of arm muscle of ME patients, it has been shown that because of an abnormal buildup of normal metabolites, the muscle cell actually shuts down to prevent cell death.**' Dr Hyde explains that this is what is happening to the true M.E. patient's cell physiology in the brain, and in muscle as a result of certain levels of physical and mental activity; there is 'cell field shutdown' to prevent the death of the cell. (Hyde 2003, [Online])

d. Dr. Paul Cheney explains that when disabled M.E. patients stand up, they are on the edge of organ failure due to extremely low cardiac output as their Q drops to 3.7 litres per minute (a 50% drop from the normal of 7 litres per minute). Without exception, according to Cheney, every disabled M.E. patient 'is in heart failure' and the disability level is exactly proportional to the severity of their Q defect, without exception and with scientific precision. (Marshall & Williams 2005, [Online].) Findings which showed mitochondrial metabolic dysfunction similar to mitochondrial encephalomyopathy also led Dr Cheney to comment, 'The most important thing about exercise is not to have [patients with ME] do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. **If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA.**' (Williams 2004, [Online]).

As these comments show, the adverse response to physical activity in M.E. patients is not 'medically unexplained.' It is also worth noting that *none* of these abnormalities can be explained by 'deconditioning' – the supposed reason for the recommendation of therapies such as GET.

The Nightingale Definition of M.E. by Dr Byron Hyde

Graduated Exercise and the Myalgic Encephalomyelitis Patient:

Possibly due to the fact that some Fibromyalgia patients can be improved by a gradual increase in exercise, or possibly due to the so called protestant ethic that all you have to do to get better is to take up your bed and walk, some physicians have extended the concept of passive or forceful increased exercise to Myalgic Encephalomyelitis patients. This is a common and potentially dangerous, even disastrous misconception.

If the M.E. patient conforms to the guidelines set out in this definition, the insurance company can only make the patient worse by instituting progressive aggressive forced physical and intellectual activity. M.E. is a variable but

always, serious diffuse brain injury and permanent damage can be done to the M.E. patient by non-judicious pseudo-treatment.

Question marks over evidential basis of claims for psychosocial therapies ME Research UK, The Gateway, Perth; and the Department of Medicine, University of Dundee

In response to an article in the British Medical Journal, we reviewed trials of the use of psychosocial therapies in ME/CFS. The total number of available trials is small, numbers are relatively low (6/8 trials have n<40 in the active groups), and 2 of the 5 cognitive behavioural therapy (CBT) trials do not show an overall significant effect. No trial contains a "control" intervention adequate to determine specific "efficacy": in only 2 trials are the treatment arms compared with an "active", though not indistinguishable, intervention. A number of non-specific effects could have accounted for the positive results, and the fact that the drop-out rate in the active arm of one of the trials was 40% may point in this direction, as discussed in one of the reviews. Again, the heterogeneity of the trials, the potential effect of publication or funding bias for which there is some evidence, and professional doubts about the evidence base for some behavioural therapies themselves give grounds for caution.

Abbot NC, Newton DJ

Letter to the British Medical Journal 2002

Sharpe and Wilks' review [1] contains an "evidence-based summary" with the statement, "graded exercise and cognitive behavioural therapies are effective in treating chronic fatigue syndrome". However, rigorous examination of the literature indicates that this remark is not itself evidence-based, a serious criticism since evidence-based summaries in the BMJ carry weight and are widely quoted. Again, the heterogeneity of the trials, the potential effect of publication or funding bias for which there is some evidence [4], and professional doubts about the evidence base for some behavioural therapies themselves [5] give grounds for caution. Indeed, if a similar evidence base existed for, say, Shamanic healing - which has no professional proponents - it would arouse little clinical interest. Neither of the review groups has commended GET or CBT as particularly effective for chronic fatigue syndrome patients. Whiting et al. [2] state, "all conclusions about effectiveness should be considered together with the methodological inadequacies of the studies."

Physiological responses to incremental exercise in patients with chronic fatigue syndrome. Inbar O, Dlin R, Rotstein A, Whipp BJ.

‘As a group, the CFS patients demonstrated significantly lower cardiovascular as well as ventilatory values at peak exercise, compared with the control group.’ ‘These results could indicate either cardiac or peripheral insufficiency embedded in the pathology of CFS patients.’ ‘We conclude that indexes from cardiopulmonary exercise testing may be used as objective discriminatory indicators for evaluation of patients.’

Chronic fatigue syndrome: assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise. Jammes Y, Steinberg JG, Mambrini O, Bregeon F, Dellioux S

‘The response of CFS patients to incremental exercise associates a lengthened and accentuated oxidative stress together with marked alterations of the muscle membrane excitability. These two objective signs of muscle dysfunction are sufficient to explain muscle pain and postexertional malaise reported by our patients.’

Profits Before Patients? Eileen Marshall and Margaret Williams, 15th April 2005

The role of the Medical Research Council (MRC) is to fund projects on the basis of expertly written, peer-reviewed and approved proposals. Clearly, therefore, the role of peer-reviewers is of paramount importance as it is they who influence what research the MRC will fund. In the case of ME/ICD-CFS there are a limited number of peer-reviewers of psychiatric interventions of cognitive behavioural therapy and graded exercise apart from the PACE trial proponents themselves, so the favourable recommendation of the carefully selected peer-reviewers was not unexpected, nor was the decision to fund the trials on "CFS/ME" patients. The PACE trials involve compulsory aerobic exercise even though the deleterious effects of such exercise on those with ME/ICD-CFS are well documented in the medical literature.

Considering the rapidly increasing weight of available published data on organic pathology in ME/ICD-CFS (little of which is published in the UK medical literature), the MRC will inevitably have its hand forced eventually, as the time will come when such evidence can no longer continue to be ignored, but currently this seems to remain a forlorn hope. Surely this is a short-sighted policy, because it is well recognised that those who are correctly diagnosed and permitted to rest adequately in the initial stages are the ones who have hope of some recovery; moreover, if relevant research were to be instituted, it would lead to patients being investigated competently and treated correctly, thus offering the prospect of ME/ICD-CFS patients being able to return to an economically productive life.

National ME / FM Action Network's 1st Annual Symposium on Parallels Between Post-Polio Sequelae, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. June 15, 2002

Dr. Dowsett believes that the polio vaccine made room for other polio-like viruses (from the family of viruses called enteroviruses) to take over. According to Dr. Dowsett's research and other work, these other viruses may even hit some parts of the brain harder than in polio. So, even if people with ME don't have (permanent) paralysis and get as physically weak as people who had polio, they may be even more impaired in other ways.

This has VERY IMPORTANT implications for assessment of disability and for treatment.

Important Treatment Information: Dr. Bruno says pacing, NOT cognitive behavioural therapy and NOT graded exercise, is the cornerstone of treatment for people with PPS and ME. The key message is that people with ME and PPS have demonstrated brain stem dysfunction. This explains a multitude of symptoms because the brain stem controls so many physical and mental processes. Dr. Dowsett supports this view. Dr Bruno is admirable in his determination to get over to people the effects of PPS, ME. and what can be done to allow people to help themselves improve their quality of life.

Politically-modified Research Eileen Marshall and Margaret Williams, 26th June 2005

'If only someone with sufficient influence would question where "Wessely School" psychiatrists get their opinions from. If this were to happen, then the rampant metastatic spread of their unproven beliefs would soon stop because their opinions are not -- and cannot be -- based on biomedical evidence. But then, "policy-based evidence" is not required to be based on biomedical evidence and that, of course, is its value to Government.'

Time to put the exercise cure to rest? by Dr Elizabeth Dowsett

There is ample evidence that M.E. is primarily a neurological illness. It is classified as such under the WHO international classification of diseases (ICD 10, 1992) although non neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised. Apart from secondary infection, the commonest causes of relapse in this illness are physical or mental over exertion. The prescription of increasing exercise is such a situation (or in the early stage of the illness when the patient desperately needs rest) can only be counter-productive.

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.

CONCERNS ABOUT A COMMERCIAL CONFLICT OF INTEREST UNDERLYING THE DWP HANDBOOK ENTRY ON MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME (THE GIBSON PARLIAMENTARY INQUIRY) Professor Malcolm Hooper, Eileen Marshall and Margaret Williams, December 2005

The information in this document is relevant to the Gibson Inquiry, specifically the continued ignoring by the Department of Work and Pensions (DWP) and its commercial advisers of the compelling scientific evidence that myalgic encephalomyelitis / chronic fatigue syndrome is not a primary psychiatric disorder. If eligibility for certain benefits becomes contingent upon the intended implementation of compulsory psychiatric "rehabilitation" regimes, in cases of authentic ME it is likely to result in serious relapse that may be life-long (and may in some

cases even result in death)

Mobility problems in ME by Dr Elizabeth Dowsett

The symptoms of this multi system disease are characterised by post encephalitic damage to the brain stem ⁽¹⁾ (which contains major nerve centres controlling bodily homeostasis) and through which many spinal nerve tracts connect with higher centres in the brain. Some individuals have, in addition, damage to skeletal and heart muscle. SPECIFIC MOBILITY PROBLEMS INCLUDE THE FOLLOWING:

NEUROLOGICAL PROBLEMS.

- a. Exhaustion, weakness and collapse following mental or physical exertion beyond the patients' capacity. This arises from metabolic damage to the reticular activating system and to the hypothalamic control of the pituitary-adrenal axis ⁽²⁾. Whereas in healthy controls or in other illnesses (such as depression) there is an increased metabolic response to exertion, in ME this is diminished, leading to sudden collapse which requires several days or more for recovery. These complications (following even trivial exercise) are not recognised in short medical examinations for social benefits and no allowance is made for the delayed effects of exertion.
- b. Recent research indicates that these patients ^(3.) have high *resting* energy requirements which further diminish their resources.
- c. Problems with balance are common in ME due to involvement of spinal nerve tracts in the damaged brain stem.

MUSCULO-SKELETAL PROBLEMS

- a. Over 70% of ME patients suffer from significant bone and muscle pain (due to disordered sensory perception – a further consequence of brain stem damage which seriously affects their mobility).
- b. Other patients have (in addition) metabolic damage to muscle fibres resulting in abnormal early lactic acidosis as demonstrated by sub anaerobic exercise tests.
- c. 30% of patients with abnormal exercise tests have evidence of persistent infection in the muscle and of muscle infarcts (tender points on pressure affecting mainly limb and trunk muscles) and of
- d. jitter (due to incoordinated muscle fibre action) on slow leg raising for example, following damage to the neuromuscular junction. A rapid decline in thigh muscle tone can be demonstrated between 2 and 24 hours after exercise ^(3.)

CARDIOVASCULAR PROBLEMS

Patients with ME suffer a variety of symptoms arising from autonomic nervous system dysfunction ^(4.) including liability to a dangerous drop in blood pressure on standing for more than a few minutes, while some 20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led, in several cases, to sudden death following exercise.

CRITICAL CONSIDERATIONS by Margaret Williams

Since as long ago as 1996 it has been known that those with ME have abnormal lung function tests, with a significant reduction in all lung function parameters tested (see "Lung function test findings in patients with chronic fatigue syndrome" De Lorenzo et al. Australia and New Zealand Journal of Medicine 1996:26:4:563-564), and Jo Nijs from Belgium presented evidence at the Wisconsin international conference of underlying lung damage in ME through intracellular immune dysregulation with impairment of cardiopulmonary function. How can forced aerobic exercise regimes be guaranteed to be harmless where there is existing underlying lung damage?

There is also evidence that many people with ME may have a serious heart problem. In April 2003, Arnold Peckerman MD from New Jersey reported findings to the annual meeting of the American Physiological Society that demonstrated via a sophisticated test that after exercise, the heart of those with ME pumped less blood than it did at rest. Peckerman is on record as saying: "Basically we are talking about heart failure. Chronic fatigue syndrome is a progressive disease". Cardiologist Joseph Miller MD from Emory University agrees that these patients have serious heart problems: "A drop in (blood pumped by the heart) during exercise is actually a marker of significant coronary artery obstruction".

What are the risks of forcing such patients to undertake aerobic exercise regimes and "push themselves back to fitness"? The ME community will recall the case of Brynmor John MP who had ME but who was advised

to exercise back to fitness; he dutifully tried to do so but collapsed and died coming out of the House of Commons gym.⁷

This excellent text from Verillo and Gellman gives a good starting point on how to start setting activity limits appropriate for your individual limits imposed by the illness. This is an excellent book and is very highly recommended – along with Dr Hyde's M.E. textbook.

Taken from Verillo and Gellman's CFS: A Treatment Guide p. 267 - 285

Single-photon emission computed tomographic (SPECT) scans have shown that in patients with [ME] who exercise, brain blood volume is reduced 1 to 3 days after exercising. In patients who are acutely or seriously ill, this could have profoundly negative effects on immune and endocrine system regulation. In patients with [ME], exercise also lowers cortisol levels, which makes it more difficult for the body to control inflammation. In addition, it increases erratic breathing and leads to a rapid progression to anaerobic metabolism, which produces ammonia and lactic acid. These negative results are the opposite of what would normally be expected.

In short, a simple answer to the exercise question is, if you are severely or acutely ill, exercise can make matters worse—in some cases, much worse. The time to discuss an exercise program with your physician is only when the illness is stabilised and clear signs of recovery are noted..

Dr. Paul Cheney remarks that "patients with this disease must, for many of them for the first time, place limits on their workstyles and lifestyles. Proper limit-setting, which is *always* individualised, is the key to improvement". This comment comes after observation of thousands of patients, many of whom denied their illness for extended periods before adjusting to its limitations. Dr. Cheney has seen not only the successes inherent in making these adjustments, but the failures that resulted from attempting to ignore them. But first, we must address the question of what is meant by "proper limit-setting."

To set proper limits, we must start with a basic awareness of how [ME] affects the body and the [brain]. [ME] affects the ability to maintain homeostasis; that is, once the illness is established, it alters the body's ability to adjust to changes in the environment. For example, a person with [ME] climbs a set of stairs and feels like he or she has just climbed Mount Everest. The out-of-breath, depleted feeling is the result of sluggish heart rate, which, in [ME] does not respond in time to greater demands for oxygen required by exertion. As a result., not enough oxygen is available, and a person with [ME] feels winded after even minimal strain. This type of delayed reaction also results from temperature changes. People with [ME] often remark that when they become cold, "it takes forever to warm up." The same is true for heat. Both temperature extremes produce symptoms as the body attempts to adjust.

People with [ME] often comment that they are either "on" or "off." Once they stop, they can't get going again; and once they start, they can't stop. In the *Clinical and Scientific Basis of ME*, Dr. Byron Hyde, a well-known clinician and researcher of myalgic encephalomyelitis (ME) describes taking a walk with one of his patients. Dr. Hyde noticed when he stopped to look in a store window, his companion kept going. When asked why, Dr. Hyde's companion replied that if he stopped, he would never get going again!

Once embarking on a project, a task, or a plan, it is difficult to stop. Even when performing easy activities such as taking a walk or balancing a chequebook, patients with [ME] often pass the point of endurance, and symptoms rapidly develop as a result.

Learning when we are "overdoing" it is how we define our own particular limits. This takes awareness, skill, and practice. **Each person has limits that are defined by the severity of the illness.** For a person who is bedbound, limits will be very different from those of someone who is able to work. Patients who are bedbound may find that extended telephone conversations, standing in the shower, or tackling stressful tasks such as filling out disability application forms produce exhaustion and a general exacerbation of symptoms. These patients may find that sitting in a plastic chair while showering, limiting conversations to 10 minutes, and resting before and after doing necessary paperwork [may help]. A patient who is mildly ill and able to work may wish to cut back on work hours, take naps, and forego activities that place excessive or inflexible demands on the body (such as team sports or other activities that do not allow the participant to "listen": to the body).

A former airline pilot refers to limit setting as living in a box. "As long as I'm in the box, I do alright. If I cross the margins of this box, I don't do very well." **Defining the limits of your own particular box is the key to developing good coping strategies.** Whatever produces a symptom on any particular day or at

any particular hour is where you would define your limits, not by any abstract assessment of what you think you should be doing or a comparison with former capacities.

Patient accounts of graded exercise therapy (GET)

These are just a small sample of many of the personal accounts available of M.E. sufferers being made very ill by exercise (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 and surveys on this topic see: [Section 6](#) of the CBT and GET database and the [Case Studies](#) section.

Name: Ruth **Country:** Ireland

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.

Graded Exercise is the worst possible thing for M.E (strictly defined). This is not to say that anybody with M.E. should not exercise, common sense tell us that it is preferable to be as active as possible, but in my experience it is critical to stay within your limits, whether that is a 20 minute walk or in my case a tightening and relaxing of my muscles 2 or 3 times a day. Having learned the hard way in future I will be allowing my body to dictate the amount of exercise I do even though that is one of the most frustrating things about this illness.

Regarding how exercise has come to be recommended by some medics, all I can assume is that they have not read the research behind the headlines, as even a cursory glance at the methodology reveals a sloppy scientifically lame approach biased towards a psychiatric model. This is wholly inappropriate for many reasons not least because M.E is classified as a neurological disease and upon closer inspection a proportion of these researchers may benefit financially from M.E being "treated" with graded exercise.

Name: Annette

I have done 2 GE programs under supervision, both were failures. They both left me far worse off than before for a long period. The first program was at a gym and involved low-impact exercises and then second was a walking program. 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.

Name: Matthew* **Country:** UK

Exercise - handle with extreme care- ruined my life.

Before becoming ill, I was extremely sporty. Initially, after not being able to rest when having a virus on a school trip at an adventure centre and made do all the activities and never recovering, I was only very mildly affected. This I put down to giving up sport because of the muscle problems I developed so for the early years, I was able to go to school and then college full-time although I had to make cut-backs in most other areas of my life and, as my brain didn't work as well, struggled.

Anyway, my condition suddenly got much worse in the middle of my second year exams (a few hours after a tough 3-hour maths exam where I pushed myself hard to do questions (got a first, by the way), my throat swelled up and I felt feverish). Kept trying to exercise during the summer but developed more and more muscle problems - the physios said they never saw anything like it and x-rays of my back showed inflammation along my spine. I took a year out of college as felt I wouldn't have been able for my finals with the health problems I had and set about trying to get back to normal health by gradually trying to build up the exercise.

Instead of improving, I kept getting worse and worse until I virtually collapsed and have been chronically and severely affected ever since and need a wheelchair to go distances more than 50 metres.

As nobody went to bed when they were sick in my house, neither did I so my symptoms in the early years could not have been put down to deconditioning.

I get so annoyed reading all the rubbish that is written about exercise and M.E. Drugs which make a significant percentage of people worse are usually banned or have big warnings yet exercise ruins the lives of lots of people with ME, like it has done mine, yet most medical people often aren't told by the people advocating the approach how dangerous it can be for patients. It really is unbelievable.

I simply can't do this treatment now. I went to all this trouble to warn others - patients shouldn't have to wait until they are harmed by a treatment to learn it is a potentially dangerous treatment - they should be able to learn from other patients. If I had come across this information years ago, I might now be living a more normal life, rather than the life of a very disabled person.

Name: Ina

Having had this DD for 30 years, nothing set me back so far as graded exercise. I have still not regained the little strength I had prior to this exercise and it has been several years.

SEVERELY AFFECTED ME (MYALGIC ENCEPHALOMYELITIS) ANALYSIS REPORT ON QUESTIONNAIRE (Word document) ISSUED JANUARY 2004 Analysis Report by 25% ME Group, 1st March 2004

Results of survey:

Graded exercise therapy: 95% found it unhelpful

Cognitive behavioural therapy: 93% found it unhelpful

By far the most unhelpful form of treatment was considered to be **Graded Exercise Therapy (GET)**. This is a finding that may surprise some readers, given the current medical popularity of this approach. However, these patients' perceptions are supported by data from previous experience: of the 39% of our members who had actually used Graded Exercise Therapy, a shocking 82% reported that their condition was made worse by this treatment. It is worth noting that some patients were **not severely affected before trying GET**. Thus, it is not only people with severe ME who may be adversely affected by this form of treatment.

SOME FACTS AND FIGURES ON CBT, GET AND OTHER APPROACHES Directly from the 'Horses' Mouths: written by Doris M Jones MSc.

In July 1998 the then Chief Medical Officer, Sir Kenneth Calman, announced the setting up of a Working Group on CFS/ME, to include patients, carers, patient group representatives as well as medical experts, including Psychiatrists. The aim was to find out what really worked in treating these conditions and based on findings, to then compile Guidelines on Diagnosis and Treatment for Clinicians and other Health Care Professionals. Over 80 people took part in this 3 year exercise, including myself. Eventually details were available on 3074 patients, and the summarized results showed very clearly that:

1. The most helpful strategies were:

- a) Pacing activity with rest (2300/2568 cases = 90%)
- b) Bed rest (2165/2426 cases = 89%)
- c) Dietary changes (1496/2226 cases = 67%)

2. The least effective strategy was: **CBT**

3. The most harmful strategy was: **Graded exercise**

Surely it is time that psychiatrists took some notice and actually listened to what patients tell them. I have yet to come across a patient who complains about any treatment which works, whether this is allopathic, psychological methods (like CBT) or exercise regimes (like Graded Exercises). If it works, no-one will complain; the problem is these approaches very often don't, and this is the one and only reason why patients are so persistent in their demands for other options and are determined to get to the real causes of their ill health. One thing is certain: psychiatrists have made things worse for many, in more ways than one.

Conclusion

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.

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

Additional notes on this text

1. A note about Myalgic Encephalomyelitis and 'CFS':

The various definitions of 'CFS' *do not* define M.E. Myalgic Encephalomyelitis is an organic neurological disorder as defined at G.93.3 in the World Health Organization's International Classification of Diseases (ICD). The definitions of 'CFS' do not reflect this. The 'CFS' definitions are not 'watered down' M.E. definitions, as some claim. They are not definitions of M.E. at all.

However, ever since an outbreak of M.E. in the US was given the label 'CFS,' the name/definition 'CFS' has prevailed for political reasons. 'CFS' is widely though wrongly applied to M.E. as well as to other diseases. The overwhelming majority of 'CFS' research does not involve M.E. patients and is not relevant *in any way* to M.E. patients. However, a very small amount (a minuscule percentage) of research published under the name 'CFS' clearly does involve a significant number of M.E. patients as it details those abnormalities which are unique to M.E. (see the end of the references section for more on this topic.)

It is important to be aware that M.E. and CFS are not synonymous terms. For more information see [What is M.E.?](#) See also [Smoke and Mirrors](#) for a discussion of why the bogus disease category 'CFS' must be abandoned. In short:

1. **Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.
2. **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.
M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely 'fatigued' instead of having M.E.' Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

Of course this 'CFS' and M.E. confusion must be stopped. It is unbelievable in this day and age that studies on a vague mixed patient group be used to determine the treatments and aetiology of an entirely different and unrelated

and distinct patient group! The only way forward, for the benefit of society and every patient group involved, is that:

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

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

The term myalgic encephalomyelitis 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. The currently version ICD-10 lists M.E. under G.93.3 - neurological conditions. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination. (2006, [Online])

People with M.E. must also be given access to basic medical care, financial support and other appropriate services (including funding for legitimate M.E. research involving 100% M.E. patient populations finally) on an equal level to what is available for those with comparable illnesses (eg. multiple sclerosis or Lupus). The facts about M.E. must again be taught to medical students, and included in mainstream medical journals, and so on.

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. [Click here](#) to read the reference list for this paper. For more information see the [References](#) page.

Before reading this research/advocacy information, please be aware of the following facts:

1. Myalgic Encephalomyelitis and ‘Chronic Fatigue Syndrome’ are not synonymous terms. The overwhelming majority of research on ‘CFS’ or ‘CFIDS’ or ‘ME/CFS’ or ‘CFS/ME’ or ‘ICD-CFS’ does not involve M.E. patients and is not relevant *in any way* to M.E. patients. If the M.E. community were to reject all ‘CFS’ labelled research as ‘only relating to ‘CFS’ patients’ (including research which describes those abnormalities/characteristics unique to M.E. patients), however, this would seem to support the myth that ‘CFS’ is just a ‘watered down’ definition of M.E. and that M.E. and ‘CFS’ are virtually the same thing and share many characteristics.

A very small number of ‘CFS’ studies/articles and books refer in part to people with M.E. but it may not always be clear which parts refer to M.E. The [A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy](#) paper is recommended reading and includes a checklist to help readers assess the relevance of individual ‘CFS’ studies (etc.) to M.E. (if any) and explains some of the problems with this heterogeneous and skewed research.

In future, it is essential that M.E. research again be conducted using only M.E. defined patients and using only the term M.E. The bogus, financially-motivated disease category of ‘CFS’ must be abandoned.

2. The research referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology. Other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as ‘CFS,’ ‘ME/CFS,’ ‘CFS/ME,’ ‘CFIDS’ or Myalgic ‘Encephalopathy’ and also include a significant amount of misinformation. Before reading

this research it is also essential that the reader be aware of the most commonly used ‘CFS’ propaganda, as explained in [A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy](#) and in more detail in [Putting Research and Articles on Myalgic Encephalomyelitis into Context](#).

“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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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 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.