

## 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 effects of CBT and GET on patients with M.E. - Condensed version

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No evidence exists which shows that cognitive behavioural therapy (CBT) or graded exercise therapy (GET) are appropriate, useful or safe treatments for Myalgic Encephalomyelitis (M.E.) patients. Studies involving miscellaneous psychiatric and non-psychiatric 'fatigue' sufferers, and their response to these treatments, have no more relevance to M.E. sufferers than they do to diabetes patients, cancer patients, patients with multiple sclerosis or any other illness. Thus, patients with M.E. are being prescribed these treatments on what amounts to a 'random' basis medically and so the questions need to be asked:

#### 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.' Many M.E. patients are housebound and bedbound and often are so ill that they feel they are about to die. People with M.E. would give *anything* to instead only be severely 'fatigued' or tired all the time. People with M.E. do not improve with exercise. They cannot; exercise intolerance is a large and essential part of *what M.E. is*.

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.' 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.'

Doctors who have experience with M.E. 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;

**1. 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.** Those who are given complete rest from the onset do well. 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' (Ramsay 1986, [Online]).

**2. 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. 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' and 'This illness is distinguished from a variety of other post-viral states by an unique clinical and epidemiological pattern characteristic of enteroviral infection. Prompt recognition and advice to avoid over-exertion is mandatory' and 'The prescription of increasing exercise can only be counter-productive.'

Dr Dowsett states about M.E. patients that, '**20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.**' According to Dr. Elizabeth Dowsett, any

M.E. patient can also be stopped from deteriorating further and at least stabilised (if not in time experiencing some level of improvement) through receiving appropriate care and being allowed to get the needed level of rest (providing that the patient has not already been exposed to unrecoverable levels of overexertion) (Dowsett & Ramsay et al. 1990) (Dowsett 2000, [Online]) (Dowsett 2001a, [Online]) (Dowsett n.d.b., [Online]).

**3. Dr Byron Hyde** explains in his M.E. textbook 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’ and that those who do not, or cannot, rest in the early stages of M.E. potentially create ‘a physical injury to the myocardium, cardiac pacemaker cells or their autonomic control.’ Dr Hyde explains 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 Cocksackie infected [enterovirus infected] mice, forced to swim to the point of exhaustion during the acute phase of infection, developed chronic heart disease whereas Cocksackie 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 other that develop major cardiac changes are never recognised as M.E.

With both CNS and CVS disease, chronicity may be provoked by maintaining strenuous exercise and work levels.. 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. [brought about by the confusion between M.E. and ‘CFS’] 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 (Hyde & Jain 1992a, pp. 375-383).

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. The world’s leading M.E. experts, namely Ramsay, Richardson, Dowsett and Hyde, (and others) have all indicated that M.E. is caused by an enterovirus. (This also includes doctors such as A. Gilliam, W.H. Lyle, Elizabeth Bell of Ruckhill Hospital, James Mowbray of St Mary’s, and Peter Behan). The evidence which exists to support the concept of M.E. as an enteroviral disease is compelling (Hyde 2007, [Online]) (Hyde 2006, [Online]).

Dr Hyde explains that enteroviral 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 (Hyde & Jain 1992a, p. 40).

An enterovirus also explains 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 (Hyde & Jain 1992a, p. 40) (Hyde 2007, [Online]) (Hyde 2006, [Online]) (Hyde 2003, [Online]) (Dowsett 2001a, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Hyde 1992 p. xi) (Hyde & Jain 1992 pp. 38 - 43) (Hyde et al. 1992, pp. 25-37) (Dowsett et al. 1990, pp. 285-291) (Ramsay 1986, [Online]) (Dowsett & Ramsay n.d., pp. 81-84) (Richardson n.d., pp. 85-92) (Richardson 1999, [Online]).

Dr Byron Hyde explains that the vascular and cardiac dysfunctions seen in M.E. are often the most obvious set of dysfunctions when looked for, and are the cause of a significant number of M.E. symptoms. Dr Byron Hyde also writes, ‘I have some M.E. 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 spectrography of arm muscle of M.E. 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]).

Dr Byron Hyde explains in The Nightingale Definition of M.E. that,

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 (2007, [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. Surveys of M.E. patients on the effects of GET illustrate the accuracy of these findings only too well:

- In 1998 a survey of over 3000 UK M.E. patients found that the single most harmful strategy was graded exercise therapy. 50% of respondents who had tried GET indicated that graded exercise had made their condition worse.. The most helpful strategies were: a) Pacing activity with rest: 90% b) Bed rest: 89%.
- In 2004 a survey of severely affected M.E. sufferers again found that graded exercise was by far the single most harmful treatment. 95% said that graded exercise was 'unhelpful' while a shocking 82% reported that it had made their condition worse. A significant number of those surveyed indicated that they were not severely affected *before* GET. Thus GET should not be considered safe for M.E. sufferers of any severity.

The way the bodies of people with M.E. react to exercise is abnormal in a number of different ways. These abnormalities are so pronounced that exercise tests are one of the series of tests which can be used to confirm a suspected M.E. diagnosis.

- See Testing for M.E. for more information about the series of tests which can be used to confirm a suspected M.E. diagnosis (including exercise tests, tests of orthostatic intolerance, and of the heart-rate using tilt-table testing and Holter monitors.)

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.

- For the full-length version of this text (which expands on each of these points) and for a full list of references for this text see: [The Ultra-comprehensive Myalgic Encephalomyelitis Symptom List](#).

Strong evidence exists to show that exercise can have extremely harmful effects on M.E. patients; permanent damage may be caused, as well as disease progression: recent research has shown that postural stress (as well as exercise) exacerbates cardiac insufficiency in this disease. Patient accounts of leaving exercise programs much more severely ill than when they began them; wheelchair-bound or bed-bound or needing intensive care or cardiac care units, are common. The damage caused is often very severe and may be either long-term or permanent. . Thus some patients are still dealing with the severe physical effects of inappropriate advice to exercise (or formal GET programs) five, ten, fifteen or more YEARS afterward and for some patients this damage appears to be permanent.

In addition to the risk of relapse, sudden deaths have also been reported in a small percentage of M.E. patients following exercise. As Dr. Elizabeth Dowsett, explains; ‘20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise.’

It is vital that M.E. patients avoid physical over-exertion and are never encouraged to be active beyond their individual limits particularly in the early and acute stages of the illness, but also at *any* stage of the illness as this can greatly damage a patient’s chances for future improvement or recovery. Graded exercise *cannot* improve authentic M.E.; disabled patients who improve with exercise do not qualify for a diagnosis of authentic M.E.

### **What is the effect of cognitive behavioural therapy (CBT) on Myalgic Encephalomyelitis (M.E.) patients?**

Compared to the physical devastation caused by GET, CBT would seem at first glance to be the softer option of the two interventions; but this is not always the case. There are two different types of CBT that M.E. sufferers may be given and the effect on patients varies greatly depending on which type is used:

1. The first type of CBT respects that there is an organic illness present which is largely irreversible (and which cannot be improved by CBT), but aims to help a patient cope better with the limitations of their illness.
2. The second type of CBT is based on the premise that the patient's impairments are entirely due to ‘wrong thinking’ and that the pathophysiology of the illness is entirely reversible and perpetuated solely by a patient’s ‘false illness beliefs.’ According to this theory the therapy is potentially curative.

Surveys of M.E. patients on the effects of cognitive behavioural therapy found:

- The (aforementioned) 1998 survey of over 3000 UK M.E. patients found that CBT was the least effective treatment covered in the questionnaire. Of those who had tried CBT, 55% indicated that the treatment had made no difference while 22% indicated that they had been made worse by CBT.
- The (aforementioned) 2004 survey of severely affected M.E. sufferers also found that cognitive behavioural therapy was one of the most unhelpful treatments for M.E. Fully 93% of those who had tried CBT said that it was unhelpful (the only treatment with a worse rating was GET).

**The hypothesis behind the first type of CBT** is reasonable. This type of CBT will likely do the vast majority of mild - moderately affected sufferers little harm (if also very little good), while a small percentage may find it useful in improving the way they cope with the illness emotionally. A significant percentage of patients will also be made worse by CBT. Even this type of CBT however (or any other), is not appropriate for any severely affected sufferer who is not physically able to cope with the physical and cognitive rigours of such a treatment. Any type of CBT will cause severe relapse in those who are severely affected in this way thus CBT can NOT be considered safe for all M.E. sufferers.

**The hypothesis behind the second type of CBT** however, is far from reasonable. This unscientific form of CBT (which ignores the demonstrated biological pathology of the illness) seeks to disregard the patient’s autonomy and experience of their illness. It tells them to ignore their symptoms. When, inevitably, this causes significant physical relapse, patients are told that this is entirely their own fault; that they must not be trying hard enough to get well and must still not be thinking ‘correctly’ about their illness. Patients are accused of ‘choosing’ to remain unwell because they are supposedly ‘enjoying the sick role.’

CBT to convince a physically ill person that he/she does not have a physical disorder is disrespectful, inappropriate and cruel. It places an additional (and bogus) psychological burden on a person already suffering with severe physical illness, and can cause significant psychological harm. M.E. expert Dr. Elizabeth Dowsett explains about CBT: ‘Whereas any regime which can encourage patients with depression to discard or distract their damaging unrealistic morbid thoughts is helpful, patients with ME are usually capable of greater insight and understanding about their illness. Unfortunately, ME sufferers are too often denied care in our society, so it is essential that they should remain as well informed as possible about treatment options and not ‘brainwashed’ into disbelieving their own symptoms.’

It is children with M.E. and their families who pay the highest price where CBT is involved however. Children with M.E. are not exempt from such interventions and this is often far more detrimental to children as compared to adults. As M.E. authors Verillo and Gellman explain: ‘To throw disbelief in the face of a child who not only

has all the symptoms of [M.E.] but is terribly frightened and in profound need of reassurance is not only cruel, it is detrimental to the child's future emotional growth.'

Equally concerning is the fact that because it is harder to pin the blame for the illness on depression or anxiety with children, the parents are often blamed instead. The 'family dynamic' may be blamed for causing the child's illness and parents of these ill children have actually been charged with neglect or accused of actually making their children ill themselves (false accusations of Munchausens by proxy). Some parents have lost custody and their children have been placed in foster care. Children have also been forcibly removed from the home and forced to undergo CBT and GET (and worse). All of this while the child continues to be seriously physically ill and not receive any sort of appropriate medical care.

This abusive form of CBT can undoubtedly cause significant psychological harm, but it is these additional associated burdens; physical relapse, the withholding of basic medical care, the removal of children from their parents and parents being falsely charged with making their children ill themselves (etc.) which combine to make this form of CBT so harmful. Thus the negative effects of CBT can sometimes be equally as devastating as those of GET, or in some cases, worse (for sufferers and their families).

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**Clearly, CBT and GET are at best useless and at worst extremely harmful for M.E. patients.** Despite this, people with M.E. are routinely being recommended these treatments while also being assured that they are completely safe. These treatments are also not just being offered to M.E. patients solely on a voluntary basis; many have been treated as psychiatric patients against their will. (Or against the will of the parents of children with M.E., as described previously). It is also of great concern that many M.E. patients are ONLY offered 'treatments' such as CBT and GET – while access to even basic appropriate medical care is withheld.

Enough people with M.E. have had their long-term quality of life destroyed – or have been killed – by the inappropriate use of these interventions. That this can be allowed to happen in such a supposedly enlightened day and age as ours defies belief. Yet the rate of people with M.E. recommended or even *forced* to exercise continues to rise, and with the full support of government, the mainstream medical community and the media.

People with M.E. must again be treated as is ethically and scientifically appropriate, and not merely in a way designed to suit certain political and financial considerations. What is happening today to people with Myalgic Encephalomyelitis is a gross violation of basic human rights.

**For more information:**

- For more information on this topic, and for references, see the full-length version of this text: [The effects of CBT and GET on patients with Myalgic Encephalomyelitis](#).
- See the paper [Smoke and Mirrors](#) for information on *why* patients with M.E. are being treated based on theories motivated by financial and political considerations rather than 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.

To print or save a copy of this text (or the entire database) in a printer-friendly Word or PDF format, see the Downloads section.

- See [What is Myalgic Encephalomyelitis? A historical, political and medical overview](#) for more information on all aspects of M.E.
- For whose benefit was 'Chronic Fatigue Syndrome' created, and for whose benefit is it so heavily promoted despite its utter lack of scientific credibility? Who benefits from Myalgic Encephalomyelitis and 'CFS' being mixed together through unscientific concepts such as 'CFS/ME' and 'ME/CFS' and Myalgic 'Encephalopathy'? Who benefits from the facts of M.E. remaining ignored, obscured and hidden in plain sight? See: [Who benefits from 'CFS' and 'ME/CFS'?](#)
- To learn more about the extreme limits imposed on M.E. patients see: [Why patients with severe M.E. are housebound and bedbound](#)
- The terminology is often used interchangeably, incorrectly and confusingly. However, the DEFINITIONS of M.E. and 'CFS' are very different and distinct, and it is the definitions of each of these terms which is of primary importance. *The distinction must be made between terminology and definitions.* For more information see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [The Terminology Explained](#) and [What is Myalgic Encephalomyelitis?](#) and [Problems with the so-called "Fair name" campaign: Why it is in the best interests of](#)

all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename 'CFS' as 'ME/CFS' and Problems with the use of 'ME/CFS' by M.E. advocates, plus The misdiagnosis of CFS, Why the disease category of '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.
- See also: Problems with 'our' M.E. (or 'CFS' 'CFIDS' or 'ME/CFS' etc.) advocacy groups (also available in an animated video format) and the new paper: M.E. vs MS: Similarities and differences
  - For more information on scams aimed at M.E. patients (similar to CBT) such as the Lightning process, Reverse therapy, Mickel therapy, EFT and so on, see Comments on the 'Lightning Process' (etc.) scam page.
  - To read a list of all the articles on this site suitable for different groups such as M.E. patients, carers, friends and family, the 'CFS' misdiagnosed, doctors or severe M.E. patients and so on, see the Information Guides page.

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

- **A note about antidepressant drugs and M.E.:** Along with CBT and GET, antidepressants are another treatment also commonly recommended to M.E. patients based on evidence involving non-M.E. patient groups and produced by vested interest groups. M.E. patients are commonly recommended or verbally forced to take these drugs on what amounts to a random basis medically. As with CBT and GET, patients are almost always incorrectly told that these drugs are a safe and effective treatment for M.E. So what effect do these drugs have on Myalgic Encephalomyelitis patients?

As with CBT and GET, they cannot improve the core problems of M.E. and can also very commonly cause serious adverse reactions. The number of M.E. patients that cannot tolerate these drugs, and for whom these drugs cause a worsening of the condition (including serious cardiac events) is very high. This is explained in more detail in the new paper: The effects of antidepressants on Myalgic Encephalomyelitis patients. (This paper is due to be completed late 2009)

#### **What can you do to help?**

People with Myalgic Encephalomyelitis have only a tiny minority of the medical, scientific, legal and other potentially supporting professions – or the public – on their side. What is needed is people from all over the world to stand up for Myalgic Encephalomyelitis – whether they are affected yet by M.E. or not. That is the only way change will occur, through education and people simply refusing to accept what is happening any more. This appalling abuse and neglect of so many severely ill people on such an industrial scale is truly *inhuman* and has already gone on for far too long. People with M.E. desperately need your help. See What is Myalgic Encephalomyelitis? and the Information Guides page

## 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. For more information see the References page.

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

Professor Malcolm Hooper 2003

‘Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis (M.E.). It is not. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance’ Dr Byron Hyde 2006

‘The term myalgic encephalomyelitis (means muscle pain, my-algic, with inflammation of the brain and spinal cord, encephalo-myel-itis, brain spinal cord inflammation) was first coined by Ramsay and Richardson and has been included by the World Health Organisation (WHO) in their International Classification of Diseases (ICD), since 1969. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination.’

Professor Malcolm Hooper 2006

‘M.E. is a systemic disease (initiated by a virus infection) with multi system involvement characterised by central nervous system dysfunction which causes a breakdown in bodily homeostasis. It has an UNIQUE Neuro-hormonal profile.’

Dr Elizabeth Dowsett

‘M.E. appears to be in this same family of diseases as paralytic polio and MS. M.E. is less fulminant than MS but more generalized. M.E. is less fulminant but more generalized than poliomyelitis. This relationship of M.E.-like illness to poliomyelitis is not new and is of course the reason that Alexander Gilliam, in his analysis of the Los Angeles County General Hospital M.E. epidemic in 1934, called M.E. atypical poliomyelitis.’

Dr Byron Hyde

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

Dr Melvin Ramsay on Myalgic Encephalomyelitis

‘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

'What all this amounts to is that we have lost any semblance indeed any pretence of pursuing scientific inquiry (into) what is true. This is almost classic in its near-phobic avoidance of considering anything that could possibly be construed as speaking the truth.'

Margaret Williams on Myalgic Encephalomyelitis

'Never in the field of human illness have so many been betrayed by so few'

RiME Sept. 2007

'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

Since Professor Cheney has shown that in M.E. patients, cardiac output struggles to meet metabolic demand, how can forced aerobic exercise help such patients remain as functional as possible? In the light of the Peckerman et al paper that was published in 2003, are the psychiatrists and their peer reviewers at the MRC who approved the PACE trial protocol still convinced that these trials (and the exercise regimes to be meted out by the new Centres) pose no harm for those with M.E.? Perhaps they are content to rely on the certainty that they themselves can never be held accountable for any harm to any patient because all participants must sign a compulsory waiver which means that no participant can ever pursue any claim for medical negligence or damages?

Professor Hooper 2007

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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.*

myalgic

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

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

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