

25 % Severe ME Group
Information for General Practitioners and Clinicians

Greg Crowhurst February 6th 2008

Introduction

Myalgic Encephalomyelitis/Encephalopathy (M.E.) is a serious biomedical disorder; only those in the final stages of terminal cancer or dying of AIDS can possibly know what it is like to experience the level of sickness that a severe ME patient has to endure for years, often decades on end .

It is a matter of record that “the most severely affected are excluded from study in the UK.” (Hooper, Marshall & Williams 2006) Recent research by the 25% Group uncovers a shocking picture of severely ill ME/CFS sufferers being labelled as psychiatric patients, being treated with contempt by GP’s, doctors and nurses, being locked in secure units and shut in AIDS wards, being refused food and being made to participate in inappropriate graded exercise and behavioural therapy, designed to convince them there is nothing wrong with them. (Crowhurst 2005)

ME/CFS is defined as “an acute onset biphasic epidemic or endemic (sporadic) infectious disease process, where there is always a measurable and persistent diffuse vascular injury of the central nervous system in both the acute and chronic phases. Primary ME is associated with immune and other pathologies.”(Hyde 2007)

ME, which can occur in both sporadic and epidemic forms, has been described in the medical literature for about 70 years.

Recognised as a specific disease entity by The Royal Society of Medicine in 1978 and by the World Health Organisation since 1969 as an organic neurological disease , ME is currently classified under ICD code G93.3. It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination (Hooper 2007)

The terms ‘fatigue’ and ‘chronic fatigue’ were not associated with this illness at all until the name was changed from ME to Chronic Fatigue Syndrome (CFS) in 1988 in the US

Since 1969, ME/CFS has been classified as a neurological disorder by the World Health Organisation International Classification of Diseases . In the 1992 revision (ICD-10) chronic fatigue syndrome (CFS) is listed as a synonymous term for ME and both terms are listed in the neurological diseases section at G93.3, hence the disorder is referred to as ME/CFS. (Hooper, Marshall & Williams 2007)

“ME/CFS” is the correct term to use for this organic disorder.

The label “CFS/ME” is wrongly applied by certain UK psychiatrists who assert ME is a mental disorder. (Williams and Hooper 2007) Following publication of the Canadian Consensus Document (Caruthers et al 2002), “it is no longer possible for any UK clinician to assert that there are no valid clinical tests for physicians to use when investigating ME patients, states Hooper (2007) “The Consensus Document lists clinical signs that address neurological, immunological, and endocrinological dysfunction and damage in ME/CFS patients that are consistent with the many symptoms described by patients with ME/CFS.”

Please note that as Hooper (2007) points out “many patients with fatigue as a major feature of their illness, for example, cancer, chronic obstructive disease, depression, and many others, are being diagnosed with CFS (Chronic Fatigue Syndrome).”

ME/CFS was recognised as a specific disease entity by The Royal Society of Medicine in 1978, and as an organic disorder by the Department of Health in 1987 (Hansard 1987) and is included in the National Service Framework (2005) as a long-term neurological condition.

Cycles of severe relapse are common in ME/CFS as are further symptoms developing over time.

ME/CFS is heterogeneous – composed of different elements and it is not clear whether ME/CFS refers to one single condition or several distinct diseases bracketed together because of the similarity of their clinical appearance.

There is still much confusion and a lack of accurate knowledge about severe ME/CFS in the medical profession, leaving many patients “dismissed and abandoned without support.” Hooper et al (2005)

According to the Chief Medical Officer (DH 2002) people with severe ME/CFS in the UK currently receive "seriously inadequate health care"

ME/CFS is characterized by (Mark 2005) :

- **malaise following even modest physical activity**
- **delayed reaction to physical and/or mental activity (up till 24 hours and more);**
- **abnormal length of convalescence (out of proportion to level of activity)**
- **varying and fluctuating symptoms during the day, but also in the course of days, weeks and months**
- **Above all, the defining characteristic of ME/CFS is cellular metabolic (Sieverling 1999) and acquired central nervous system dysfunction (Hyde 2003)**

There is a significant body of compelling published evidence, demonstrating the involvement of the central nervous system, the autonomic nervous system and the peripheral nervous system in the pathogenesis of ME/CFS, as well as immunological and vascular disruption. (Hooper, Marshall & Williams (2006)

Objective evidence of quantifiable organic abnormalities in Myalgic Encephalomyelitis patients has existed since the 1950's. (Bassett 2006) According to Professor Komaroff, a renowned world expert on ME/CFS, there are more than 4,000 papers which demonstrate that ME/CFS is an organic, not psychiatric, disorder (Hooper et al 2005).

What ME/CFS is not :

ME/CFS and **Chronic Fatigue** are not the same. ME is formally classified as a neurological disorder in the International Classification of Diseases (*ICD10:G 93.3; WHO 1992*), and the ICD separately classifies fatigue syndromes as a behavioural (psychiatric) disorder (*ICD 10:F 48*) Researchers have failed to distinguish between ME and CFS and/or between subgroups. (Anon 2001) As Carruthers & van de Sande (2005) point out : “ Chronic fatigue must not be confused with ME/CFS because the ‘fatigue’ of ME/CFS represents pathophysiological exhaustion and is only one of many symptoms.

ME/CFS is not a **somatoform disorder**. The documented biochemical, metabolic, vascular, neurological and muscle abnormalities in ME/CFS patients (Williams 2004) have led to the WHO classification of ME/CFS as a neurological illness. The UK Department of Health and the WHO Collaborating Centre at the Institute of Psychiatry have agreed that ME/CFS is undoubtedly neurological. There is no published evidence whatsoever, as opposed to opinion, that ME (as distinct from chronic fatigue) is a psychiatric disorder. (Williams 2004). Unlike somatisation disorder, M.E. is not ‘medically unexplained.’ M.E. is a multi-system disease with many organ and bodily systems affected, producing a myriad of symptoms [and] many aspects of the pathophysiology of the disease have, indeed, been medically explained in volumes of research. (ME Society of America)

ME/CFS is not “cured” by **Cognitive Behavioural Therapy (CBT) and Graded Exercise (GET)**. CBT and GET are not accepted in the British Formulary for ME and therefore cannot be considered automatically to be within the legal framework for treatment, especially for the severely affected. (25% Group 2005) CBT and GET are potentially harmful to anyone with neurological ME. The Chief Medical Officer (2002) has warned that exercise-based regimes advocated for less severely affected patients tend not to have been studied among those most severely affected. Shepherd (2001) warns that as much care should be taken in prescribing exercise as in prescribing pharmaceuticals for ME/CFS patients do not respond to exercise in a manner that is expected of healthy people (Streeten et al 2001) For the first time evidence of raised levels of isoprostanes, highly noxious by-products of abnormal cell membrane metabolism, associated with exercise, that precisely correlate with patients' symptoms has been presented (Kennedy, Spence & Belch et al 2005).

It is not '**fatigue**' or '**tiredness**' that is the one essential characteristic of ME/CFS but central nervous system (CNS) dysfunction (Bassett 2006). As leading M.E. expert Dr Byron Hyde MD (2003) explains: 'The one essential characteristic of M.E. is acquired CNS dysfunction, [not] chronic fatigue. A patient with M.E. is a patient whose primary disease is CNS change, and this is measurable. We have excellent tools for measuring these physiological and neuropsychological CNS changes: SPECT, xenon SPECT, PET, and neuropsychological testing.' Drs Cheney and Peterson describe ME/CFS as ‘A global disablement, nearly

comparable to paralysis.’ (Johnson 1996) Dowsett comments that “Fatigue” is the wrong word. Fatigue is a silly word.’ (Colby 1996) Dr David Bell M.D (1995) describes the word “fatigue” as: 'A very inappropriate term for what patients experience. It's not really fatigue at all, which is defined as a normal recovery state from exertion and that is precisely what does NOT happen in this illness. ‘ In 2003 The Canadian Expert Consensus Panel published a medical milestone, the first clinical case definition for the disease known as myalgic encephalomyelitis/chronic fatigue syndrome, making it compulsory that in order to be diagnosed with ME/CFS, a patient must become symptomatically ill after exercise and must also have neurological, neurocognitive, neuroendocrine, dysautonomic, and immune manifestations. In short, symptoms other than fatigue must be present for a patient to meet the criteria. (Carruthers et al 2003)

ME/CFS is not **depression**. Research, for example, shows that CFS patients show more alpha electroencephalographic activity during non-REM sleep, but this is not seen in dysthymic or major depressive disorder (Whelton, Salit, & Moldofsky, 1992). Cognitive changes are also not due to psychiatric co-morbidity (Vercoulen et al 1998 Backwood et al 1998) SPECT cerebral blood flow studies of persons with CFS show decreased blood flow in several key areas such as frontal lobes and brain stem which are different from both healthy controls (Barnden et al, 2001Costa et al, 1995) and depressed subjects (Schwartz et al, 1994; Fischler et al, 1996). PET scan studies have reached similar conclusions (Tirelli et al, 1998). Bakheit, Behan, Dinan, Gray, and O'Keane (1992) found up-regulation of hypothalamic 5-hydroxytryptamine receptors in patients with postviral fatigue syndrome but not in those with primary depression. Hickie (1991) found that general characteristics of depression: anhedonia (lack of pleasure in life); weight loss; suicidal ideation; severe psychomotor change; pathological guilt; and severe anxiety, are not typical in ME/CFS.

Epidemiology

The population prevalence of CFS/M.E. is 0.2% – 0.4%.

It is about twice as common in women, and affects all social classes and ethnic groups.

Prognosis

Cycles of severe relapse are common, as are further symptoms developing over time. Around 30% of cases are progressive and degenerative and sometimes ME/CFS is fatal. (National CFIDS Foundation). Two recent reviews have concluded that, “Substantial improvement is uncommon and is less than 6%” (Anderson et al. 2004); and, "Full recovery... is rare" (Cairns & Hotopf, 2005).

Various immune, endocrine, musculoskeletal, and neurological abnormalities have been described which could be primary processes or secondary consequences.

A rapid and dramatic deterioration of health in acute onset cases often occurs while others have gradual onset with no obvious cause.

Symptoms

The Canadian Expert Consensus Panel have published a medical milestone, the first clinical case definition for the disease known as myalgic encephalomyelitis/chronic fatigue syndrome which **is summarised as follows:**

1. POST-EXERTIONAL MALAISE AND FATIGUE: There is a loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue, malaise and/or pain, and a tendency for other symptoms to worsen. A pathologically slow recovery period (it takes more than 24 hours to recover). Symptoms exacerbated by stress of any kind. Patient must have a marked degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

2. SLEEP DISORDER: Unrefreshing sleep or poor sleep quality; rhythm disturbance.

3. PAIN: Arthralgia and/or myalgia without clinical evidence of inflammatory responses of joint swelling or redness. Pain can be experienced in the muscles, joints, or neck and is sometimes migratory in nature. Often, there are significant headaches of new type, pattern, or severity.

4. NEUROLOGICAL/COGNITIVE MANIFESTATIONS: Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, difficulty with information processing, categorizing, and word retrieval, intermittent dyslexia, perceptual/sensory disturbances, disorientation, and ataxia. There may be overload phenomena: informational, cognitive, and sensory overload -- e.g., photophobia and hypersensitivity to noise -- and/or emotional overload which may lead to relapses and/or anxiety.

5. AT LEAST ONE SYMPTOM OUT OF TWO OF THE FOLLOWING CATEGORIES:

AUTONOMIC MANIFESTATIONS: Orthostatic Intolerance: e.g., neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension, vertigo, light-headedness, extreme pallor, intestinal or bladder disturbances with or without irritable bowel syndrome (IBS) or bladder dysfunction, palpitations with or without cardiac arrhythmia, vasomotor instability, and respiratory irregularities.

NEUROENDOCRINE MANIFESTATIONS: loss of thermostatic stability, heat/cold intolerance, anorexia or abnormal appetite, marked weight change, hypoglycemia, loss of adaptability and tolerance for stress, worsening of symptoms with stress and slow recovery, and emotional lability.

IMMUNE MANIFESTATIONS: tender lymph nodes, sore throat, flu-like symptoms, general malaise, development of new allergies or changes in status of old ones, and hypersensitivity to medications and/or chemicals.

Evaluation and diagnosis

Although, as with lupus, multiple sclerosis and ovarian cancer for example, there is no medical test available to confirm a diagnosis of M.E, it is absurd to claim no objective or quantifiable abnormalities can be found in patients with severe M.E. (Bassett 2006) “Tests will only all be normal in M.E. patients – as with all illnesses – if completely the wrong tests are done, or if those tested do not in fact have M.E. in the first place.” (Bassett 2006) .

Tests which can aid diagnosis include :

- **SPECT and xenon SPECT scans of the brain : to measure decrease in cerebral blood flow, especially 24-48 hours after exertion.** Recent studies have shown that 80% of ME/ICD-CFS patients will have abnormal SPECT scans. These abnormalities have also been shown to correlate with clinical status. (Carruthers et al. 2003)
- **MRI scans of the brain :** Punctate, subcortical areas of high signal intensity consistent with edema or demyelination were identified by MRI in 78% of ME/CFS patients (similar to those seen in MS). The abnormalities in M.E. patients most closely resemble those seen in AIDS encephalopathy. Research has shown that 50% - 80% of ME/CFS patients will have abnormal MRI scans. (Hyde, 2003) (Carruthers et al. 2003)
- **PET scans of the brain.** PET scans have shown decreased metabolism of glucose in the right mediofrontal cortex. PET scans have also shown generalised hypoperfusion of the brain with a particular pattern of decreased neuronal metabolism in the brain stem. (Carruthers et al. 2003)
- **Neuropsychological testing : to measure cognitive function.** Bastein (1992)
- states : “ Deterioration of IQ levels, as well as cognitive and motor dysfunction in these patients, suggest a pathological process in the brain. The pattern of focal and lateral impairments is consistent with patients who have this particular neurologic dysfunction. The impairment pattern is consistent across the study group [of M.E. patients] although impairment levels vary. This pattern is not seen in other diseases or injuries.”
- **EEG brain maps and QEEG brain maps** 95% of ME/ICD-CFS patients have been found to have abnormal cognitive-evoked EEG brain maps (Hooper, 2001)
- **Romberg or tandem Romberg test :** ‘In his 1995 Australian Workshop, [ME/ICD-CFS expert Dr Paul] [HYPERLINK "http://www.ahummingbirdsguide.com/wcheney.htm"](http://www.ahummingbirdsguide.com/wcheney.htm) **Cheney** said that more than 90% of patients have an abnormal Romberg versus 0% of controls.’ (Hooper et al.

2001)

- **Tests of the immune system** : The immune system abnormalities in M.E. patients mimic the immune pattern seen in viral infections. (McLaughlin,) (Carruthers et al. 2003) (Hooper et al. 2001)
- **Physical Examination** : In a recent 25% Group survey of the most severely affected (Crowhurst 2005) 71% of respondents reported that they experience 20 or more severe autonomic, endocrine, neurological and immune system manifestations each. Physical signs of illness commonly observed in ME/ICD-CFS patients include: *Nystagmus*; nystagmus is jelly-like and variable (15% of M.E. patients will have nystagmus) , *Sluggish visual accommodation* , Unequal pupils and contrary pupil reaction to light; *A labile blood pressure* (sometimes as low as 84/48 in an adult at rest) ; *Shortness of breath* (particularly on exertion) ; Sometimes *marked falling pulse pressure* in arterial pressures taken first when prone, then sitting, then standing ; *Rapid heart rate* on minor activity such as standing; *Subnormal temperature* ; Patients show significant reduction in all lung function parameters tested; *Liver involvement* (an enlarged liver or spleen) ; *Abnormal tandem or augmented tandem stance*; *Abnormal gait* ; *Hand tremor* ; *Incoordination*; *Cogwheel movement* of the leg on testing ; *Muscular twitching* or fasciculation ; *Hyper-reflexia* without clonus ; *Facial vasculoid rash*; *Vascular demarcation* which can cross dermatomes with evidence of Raynaud's syndrome and / or vasculitis and spontaneous periarticular bleeds in the digits ; *Mouth ulcers* ; *Hair loss*; *Atrophy* of fingerprints is due to perilymphocytic vasculitis and vacuolisation of fibroblasts ; *Ghastly pallor* of face with frequent lupus-like submaxillary mask ; *Parkinsonian rigidity* of facial expression; *Scanning, disjointed speech*, or speech reversals ; *Nasal passage obstruction* and inflamed areas around tonsillar pillars ; *Sicca syndrome* of conjunctiva and mucous membranes ; *Frequent equivocal Babinski/plantar reflex* on one side ; *Unusual sensitivity of cervical vertebrae area*; (Hooper et al. 2001) (Hyde, 2003)

It is very important that a diagnosis is reached as early as possible (ie. within a period of between 3 – 6 months) so that appropriate advice and treatment can be started as early as possible.

Doctors and clinicians can help by: (extract from CMO Report Annex p.12)

- **listening** to the patient, recognising and believing his or her individual experience
- **acknowledging uncertainty** and the impact that this has on the patient, family, and carers
- **providing support and encouragement** – e.g. during setbacks
- **providing information** on and discussing the nature of the condition, approaches to self management, helpful therapies, and how to access other agencies and services
- **agreeing upon a name for the condition**
- **giving advice** on symptomatic treatment

Onset

According to Byron Hyde (2006) Myalgic Encephalomyelitis is:

- 1 A variable and biphasic acute onset disease.
2. Primary Infection Phase: The first phase is an epidemic or endemic infectious disease generally with an incubation period of 4 to 7 days, where in most, but not all cases, an infection is evident.
- 3 Chronic Phase: The second and chronic phase follows closely on the first phase, usually within two to seven days, and is characterized by a measurable diffuse change in the function of the CNS. This is the persisting disease that most characterizes M.E. (Hyde (2006) Little Red Book

Symptom control

Everyday life for the severe ME sufferer is a perpetual struggle. As Owen (2007) points out the most severely affected may not be able to speak, eat, swallow, open their bowels. They may not be able to sit up or move themselves, they may be too exhausted to dress or wash. The sound of running water even may be too much for them to bear, they may not be able to open their mouth to brush their teeth.

Bassett (2005) comments how : “More than 64 distinct symptoms have been authentically documented in ME/ICD-CFS. (Hooper & Montague 2001). At first glance it may seem that every symptom possible is mentioned, but the seemingly random list of symptoms in fact form unique and distinct patterns – they are anything but ‘random’ for those with knowledge of the illness and/or of how the illness effects the body’s various systems.

A list of typical ME/CFS symptoms may include : :

Tender lymph nodes

Sore throat

Flu-like symptoms

General malaise

Post – exertional fatigue

Development of new allergies

Hypersensitivity to medications/chemicals

Loss of thermostatic stability

Heat/cold intolerance

Anorexia or weight gain

Food sensitivity

Hypoglycaemia

Worsening of symptoms with stress & slow recovery

Emotional Lability

Postural hypotension
Vertigo
Head ache/pain
Visual disturbances
Light headiness
Extreme pallor
Intestinal dysfunction
Bladder dysfunction
Respiratory irregularities
Difficulty with information processing
Perceptual/sensory disturbances
Photophobia
Hypersensitivity to noise
Pain
Transient Paralysis
Pins & Needles
Numbness
Unrefreshing sleep
Speech difficulties
Swallowing difficulties
Spasms

(Adapted from the Canadian Definition - Carruthers B et al (2003))

In a recent survey (n=21) conducted by the author (Crowhurst and Crowhurst 2007) ,the smallest number of symptoms experienced per severe ME sufferer was 12 and the maximum number of symptoms experienced was 37, the average number of symptoms experienced per person was 25.

The predominant psychiatric paradigm, still seems to be that patients have medically unexplained chronic fatigue, and that their problems derive from deconditioning consequent on physical inactivity at best, and simple avoidance behaviour (underpinned by abnormal illness beliefs) at worst.. (Scottish Cross Party Submission 2005). What happens in ME/CFS, however, has little to do with cardiovascular deconditioning . Goudsmit (2005) points out that studies have shown that most patients do not avoid minimal activity and that lack of fitness is not related to the fatigue in ME/CFS (Bazelmans et al 2001) . Moreover, deconditioning cannot explain the documented delay between the end of exertion and the exacerbation of symptoms, the upregulated immune system etc. (De Merlier et al 2000

For many people the symptoms are not controlled in ME : **please see Appendix 1 .**

.Pain “is a severe symptom which is difficult to treat and is usually due to dysfunction of the thalamus, an important sensory relay station in the brain stem. Failure to produce natural painkillers (e.g. endorphins and enkephalins), may be an additional factor.” (Dowsett). There are many levels of pain suffered in ME and they can occur simultaneously :

There is a typical worsening of symptoms with stress . This, says Dr Dowsett, probably “arises from injury to the brain stem which normally controls the production of cortisol (a steroid required for stress control) via the hypothalamus, pituitary and adrenal glands . In the absence of an efficient response, even minor stress can cause catastrophic collapse in these patients. NB. Because of the many and varied symptoms arising from encephalitic damage to the brain, all symptoms reported, however bizarre they may seem, must be taken as possible evidence of organic disease.”

Cognitive difficulties, problems in processing information are a major issue in ME. It is well established, even among groups positing a psychological cause for ME/CFS, that objective cognitive changes have been found , Vercoulen et al (1998) found that test subjects could be correctly classified as ME/CFS based on the cognitive test results. Cognitive changes are not due to psychiatric co-morbidity (Vercoulen et al 1998, Backwood et al 1998) SPECT cerebral blood flow studies of persons with CFS show decreased blood flow in several key areas such as frontal lobes and brain stem which are different from both healthy controls (Barnden et al, 2001;Costa et al, 1995) and depressed subjects (Schwartz et al, 1994;Fischler et al, 1996). PET scan studies have reached similar conclusions (Tirelli et al, 1998).

The Chief Medical Officer stressed how : “Care of people who are severely affected is an urgent challenge that must be addressed in appropriate and imaginative ways, drawing from service models applied to other severe chronic disabilities. Healthcare and social service professionals are responsible for finding ways of supporting and guiding patients and their carers for the duration of illness, ensuring access to available support, keeping in contact, constantly re-evaluating the options, maintaining morale, enabling respite, and minimising consequences of prolonged disease.”

As Byron Hyde (2006) points out ME is : “a discipline that requires physicians who are totally dedicated full time to the understanding of these patients, as are the specialists in any area of medicine. This should be our aim.

Pharmacological Interventions

People with ME/CFS are often extremely sensitive to pharmacotherapy; even though this is denied in the NICE Guideline, a complete rejection of the patients’ experience.

Treatment and rehabilitation

There are no known appropriate treatments available at this time and it has been found that some of the so-called mainstream therapies applied to ME sufferers have been unhelpful or harmful on many occasions (especially treatments such as Cognitive Behavioural Therapy and Graded Exercise Therapy). Of those who tried Graded Exercise, 95% of Respondents, in a 25% Group survey, reported that it had a negative impact on them and 96% reported that Cognitive Behaviour Therapy had a negative impact. (Crowhurst 2005)

Pacing, which has its roots in the pioneering work of Ramsay, Parish and Dowsett, was adapted by Goudsmit in the mid-1990's as the complete opposite of Graded Exercise Therapy (GET). Pacing is common sense and has very much indeed to commend it; as Dr. HoYen advises: "learn to listen to your body. It will tell you when there is a problem" Sadly the concept - simple though fiendishly complex in practice, is often wrongly interpreted in the UK - there is no evidence, for example, of the effectiveness of the 'target and plan approach' to Pacing, as widely advocated by the psychiatric lobby, nor of the "boom and bust" theory.

NICE recommends "rehabilitation" as the core management regime across the board for every person in the UK with mild or moderate ME/CFS. This is irrational and could easily become abusive practice as opposed to supportive enablement, since it has already been shown by major UK surveys of over 3,000 patients that CBT/GET may convert moderate ME/CFS into lifelong severe ME/CFS and that GET was the intervention most likely to make patients worse.

Activity Management

"Activity management", is based upon the three principles of: prioritising, planning and pacing (O'Hara 2002) It should be stressed that while pacing is generally welcomed by patient groups, the use of Graded Exercise Therapy is controversial. Nolan (2007) for example, outlines how in submissions to NICE, The British Psychological Society said that "there is no evidence that GET (with or without CBT) actually increases activity levels", the Royal College of Physicians said "Clinical evidence and patient experience suggests strongly that some patients may be worsened with GET", while the Association for British Neurologists said that "the guideline needs to be thoroughly revised to reflect our current understanding of this condition rather than the supposition of the psychiatrists".

Exercise-based regimens advocated for less severely affected patients tend not to have been studied among those most severely affected. Graded exercise therapy (GET), cognitive behaviour therapy (CBT) and pacing – learning to successfully manage activity and rest intuitively – might help some people with CFS/M.E. However, it is misleading to consider CBT, GET or pacing as treatments – they are management or coping strategies. While strategies such as pacing appear to make sense, the situation in severe CFS/M.E. is complex (Crowhurst, 2005).

NICE specifies that the intensity of GET should be incrementally increased, leading to aerobic exercise (1.6.2.3). Professor Paul Cheney (1999) warns that in relation to ME/CFS patients: "The most important thing about exercise is not to have them do aerobic exercise. I believe that even progressive aerobic exercise, especially in phase one and possibly in other phases, is counter-productive. If you have a defect in the mitochondrial function and you push the mitochondria by exercise, you kill the DNA".

It must be stressed that treatments offered to less severe patients, including CBT, GET and pacing are not appropriate in Severe CFS/M.E.

Approach to management

When planning how to care for the ME/CFS sufferer; the guiding factor should always be that these patients are seriously ill.

It is essential to adopt a positive outlook and to work constructively and creatively with patients who have severe ME/CFS. The doctor who is willing to work in partnership and communicate sensitively with patients, developing a trusting, caring and professional relationship can make a real difference to the quality of life of these patients.

Special difficulties arise from being physically unable to access the many services that now require patients to be ambulant, or to travel to the point of service assessment or delivery. Immobility and isolation can easily lead to what some people describe as 'invisibility'.

Successful management of any long-term illness includes the patient as a partner in their own care, resulting in greater self-reliance, better adherence, higher satisfaction, and greater continuity of care.

A partnership approach acknowledges that patients must cope continuously with their illness.

You need to try and work as best you can with the person. This means learning to understand what they need, when they need it and how they need it. It may not always be obvious.

You need to understand their symptoms and the impact they have on the person so that you will better understand their reaction to you.

- If you speak too loudly for example you might get an irritated response, or the person might put their head under the bed clothes because the noise has distressed, hurt or disturbed them.
- You need to be aware that when moving around in proximity to the person you may well be being noisy in relation to the person, even if you are not aware of the noise yourself. Understanding the need for silence and a quiet voice may make all the difference to how you get on and how helpful

You therefore need to work together to build up trust and respect and a relationship that works for you both.

When helping someone with severe ME you need to be :

- prepared
- calm
- centred

- focussed on what you are doing and the person's reaction
- open to change, stop, be more gentle, willing to try something else.

ME/CFS sufferers do not want :

- **A behavioural "therapy"-led service**
- **To be "lumped in" with other undefined chronic fatigue illnesses and states.**
- **A psychosocial model of care.**
- **To be offered psychosocial CBT/GET 'treatments', as these have been shown to be dangerous for severely affected patients and cause setback and worsened prognosis for milder cases of ME.**
- **To be patronised by ill-informed medical professionals who do not believe that they have a physical disease.**
- **To be downgraded and treated as if their very real and severe neurological symptoms, such as paralysis, spasms, parasthesia and pain are insignificant or psychiatric in origin.**
- **To be offered psychiatric - originated management techniques, charading as treatment for this physical illness.**
- **To be described as "tired".**
- **A fudging or a pretending to meet the needs of people with ME, but actually working to a psychiatric paradigm that is rooted in vested interest and based upon pseudo-science and flawed patient selection criteria.**

ME sufferers want medical professionals to :

Honour the fact that ME is a serious neurological disease (WHO ICD 10. G93).

Acknowledge that 'Myalgic Encephalomyelitis' is a World Health Organisation (WHO: ICD 10 - G93.3) defined neurological disease and is not the same condition as 'idiopathic chronic fatigue' described separately by the WHO at ICD -10-f.48.

Use an appropriate biomedical definition that takes account of the above and accords with international research evidence, expertise and proper WHO illness category demarcation.

Actively educate other clinicians, paramedical staff and social and child-education services regarding the true physical nature and impact of this disease.

Use the primary WHO-listed name "Myalgic Encephalomyelitis" , as opposed to "CFS, Chronic Fatigue or Encephalopathy" (Hooper 2007)

Respect the fact that ME is a multi-system disease affecting all systems of the body :

Acknowledge that biopsychosocial CBT/GET treatments are deemed inappropriate at best

and contraindicated at worst by leading international specialists and consensus diagnostic and treatment protocols

Be particularly aware of the severity of severe ME symptoms and the high level of post exertional malaise and post- exertional fatigue experience and accommodate it; so that patients can be seen and given proper ongoing support.

Validate the ME sufferer's experience through adequate biomedical testing :

Recognise the symptoms of real ME, their impact. and make appropriate recommendations, based on current physical research and state-of-the-art practice.

Offer appropriate biomedical tests and scans that prove that the severe ME sufferer has a physical illness and illuminates what is going wrong in their body.

Provide appropriate state-of-the-art biomedical assessment that will provide a medically-informed and scientifically objective report about the illness and disability.

Give patients the opportunity to choose to participate in physical research so that people who have Severe ME can be reflected in any research evidence compiled , in the hope of promoting better patient outcomes and disease prevention.

Treat the symptoms as much as possible :

Explore, prioritise and validate the neurological symptoms of ME..

Provide home visits from a biomedical clinician for those not well enough to travel.

Have the ability and funding to prescribe drug and nutritional interventions for illness management (e.g. pain relief and sleep promotion) and, where possible, for better prognosis (e.g. appropriate antiviral treatments).

Acknowledge that all other treatments/ therapies should be agreed with the input and agreement of the ME specialists as principle advisors- due to their understanding of possible adverse reactions, complications etc. This particularly applies if there are also mental health/ conditions/ complications.

Competently provide support :

Acknowledge the genuine severe disability so that support can be given to sufferers to claim benefits and grants etc, to enable true entitlement.

Offer advice based on awareness to ensure safe practice and safe treatments regarding how to deal with other medical conditions and illnesses that might arise.

APPENDIX 1

The reality of living with severe Myalgic Encephalomyelitis 2 September 2007

<http://www.bmj.com/cgi/eletters/335/7617/446#175682>

Linda A Crowhurst,
Severe ME sufferer

The recently published NICE guidelines (Aug 22) on "CFS/ME" are shameful, they offer nothing to true ME sufferers.

ME; it is waking up in intense unbearable unbelievable pain for 14 years and knowing it's going to probably be the same forever not because it has to be like that but because it is being manipulated like that.

Having severe ME is unimaginable ; the experience is so different , intense and unremitting than anything I have ever experienced before.

I am never unaware of the range of symptoms that rage through my body , and are overwhelmingly dominated by intense never ending pain in every millimetre of my skin and muscles, over and throughout my whole body; head shoulders, back, front , arms legs, hands , feet, toes , fingers, eye lids , scalp the soles of my feet, the tip of my nose , my eyebrows even.

They all burn, throb, tingle, itch, and hurt in ways indescribably unbearable , along with other unusual sensations that flow and ebb, expand and contract, and irritate beyond belief. My throat hurts, my eyeballs are swollen and itch , prickle, burn, throb , unceasingly,

My ears hurt to touch inside and out and noise, even a whisper can be excruciatingly loud and painful. Street noise, cars revving, doorbells, telephone, dogs barking, conversations at normal sound levels , all can torment me. The screeching sound of knives and forks on plates, the sound of people chewing even are exaggerated by my hyperacusis .

Any regular sound is intolerable such as a clock ticking, a newspaper rustling, a plastic bag being opened, or someone banging, a lawn mower , a Hoover send out devastating sound vibrations that I feel not only in my ears but in my whole body as pain. I become completely alienated from the world I seemingly and supposedly exist in.

I cannot bear to see people because they exhaust me with questions and conversation, with thudding foot steps, loud voices; they irritate me with their insensitivity and unawareness of my hypersensitivity, and hurt me physically – a hug or a pat on the back can be like a huge blow.

Light is intolerably bright, television and computer screens hurt my eyes, reading anything causes my brain to somehow overload so that I cannot receive or process information . Written or verbal descriptions both have the same affect. Letters jump around the page or make no sense or shape at all.

I stare a lot because it is too painful to focus. I say yes or nod when I cannot even understand the conversation because it is making no sense and my mind has become a fog of nothingness.

My head has a huge pressure on top with the deepest of throbs that incapacitates me completely physically and mentally. I often feel as if someone has driven a wedge down the centre of my head so there is no awareness inside it where I should be able to think perceive visualise imagine.

As I lie down I feel not only my head throbbing in unstoppable pain waves , but also my hands, my feet, my calf muscles, my face , my lips, my whole body is actually throbbing in unison.

As I lie down too weak to sit up any longer, my muscles spasming and seeming like jelly too insubstantial to hold my back upright, I find that I cease to function in even the most basic of movements. I cannot move my fingers. I cannot move my legs or my arms. i cannot reach the glass of water by my bedside despite I am gasping with thirst and my mouth is parched dry. My eyes are dry too, the tear film will not stay covering it so that moving my eyeballs is like rubbing them with sandpaper. Often it seems as if i am looking down a dark tunnel. I do not have full vision.

As I fall into sleep or near sleep mode my whole body ceases to move completely and totally. When I sleep I am still semiconscious for a lot of the time, the pain in my body penetrating my awareness or tormenting me with lucid dreams in Technicolor. In the deepest sleep I might feel innerly peaceful but then struggle to reawaken.

As consciousness arises I discover I cannot move my eyelids, I cannot open my mouth or speak to call out for help. My breathing is uneven and difficult with my diaphragm muscles struggling to move evenly and properly. My whole body pain has intensified to a vast degree . There is no possibility of movement of any kind. There is no response to any voluntary command to move. My whole body is an immovable throb of burning pain . My face has become palsied. Whole areas of my skin have become numb, particularly severe is my left side, especially my left ear neck , face and arm, though sometimes oddly enough it switches so that my right side is worse. I have left sided head pain which is intensified greater on that side, for it is still present on the other side too. My lips are numb , my nose is numb , my eyeballs feel numb and grotesquely enlarged. I cannot even move my littlest finger let alone my hand. My feet are numb and my limbs are cold.

I lie like this with my bladder bursting, desperate to go to the toilet yet unable to call for help and unable to bear being touched or moved. Any attempt to move me will cause me to spasm and go into such agony that I cannot tolerate it. And so I wait. I wait and wait until touch becomes more bearable, till speech becomes possible, till fingers can be moved and limbs manipulated and knees will lock so that I can hopefully sit then eventually stand with support . The wheelchair waits but motion brings new difficulties. standing brings dizziness and black outs, Motion brings vibration and impossible irritation .

Once I have moved a little I may be able to move a little more, but the pain never ever goes away. It is constant in my life and everything I do is filtered through this experience of pain, numbness , muscle dysfunction and acute hypersensitivity. No activity or action is enjoyable physically.

There is no position that does not hurt.

There is no seating that is comfortable, the pain does not miraculously go or decrease because I lie down – I am in physical discomfort to physical torment every moment in every position.

On top of this general all over intense pain I have a damaged hip from a bad osteopathy experience, I have a damaged cartilage in in my knee but my body is too weak to be operated on and my drug and chemical sensitivity plus my sleep paralysis and breathing difficulties make an operation impossible, I have severe period pain, I have painful, tender to touch, throbbing guts and IBS type symptoms, I have a damaged

lower back and recently I have hurt my shoulder.

I have food sensitivities and drug allergies, I have all over body spasms, I have dental work that I am too ill to have done, I have low level thyroxin, I have low cortisol levels. I have had severe anaemia for the last 2 years . I experience hypoglycaemia regularly. I feel ill all the time and I feel worse after minimal effort.

I have been told I have less than 20% functional ability at best and less than 10% at worst. I have a severe and chronic neurological disease that is acknowledged by the World Health Organization (WHO) at ICD10.9.3.

I am unable to manage without physical assistance and have to live in silence and stillness with very little outside contact. because I have such little energy and such severe symptoms. I regularly burn myself because I cannot accurately tell the temperature of hot things such as bath water, hot water bottles. I fall over often and bump into things because I have poor balance, poor spatial awareness and proprioception, poor coordination and I get dizzy.

My muscles simply do not work properly. I drop things. I often and daily cannot hold things, like knives, forks, pens, telephones, All my cups and cutlery need to be light or they hurt me to lift.

Standing is difficult and hard to explain why , unless you understand the orthostatic intolerance present in ME. My symptoms worsen after any exertion and I completely run out of energy and have to go back to bed.

Walking varies from completely impossible to severely limited . I have a wheelchair for indoor and outdoor mobility yet it is still often unuseable because of the complexity of symptoms I experience.

Although I live in a beautiful place I have never been able to walk to the village shop, the post office ,go cycling, go to the pub, the many restaurants, the church services, the cinema, the theatre, go bird watching, go on the local sandy beaches, .

Having ME means you lose friends and it is virtually impossible to make new ones because contact is so hard to maintain and normal social events are a torment that become impossible to participate in. You cannot join in family occasions or celebrations – and in the end

people stop inviting you, they stop expecting you and often they blame you rather than continue to reach out in new ways to understand the illness. Holidays are impossible because of poverty, difficulty with travelling, unsuitably hard beds, potential intolerable environmental noise, chemical sensitivity, and inaccessibility to everything.

Visiting others is another virtual impossibility because of multiple sensitivities and just feeling so very very ill all the time. Planning anything is utterly impossible because you never know from moment to moment what you can physically manage. and keeping appointments is extremely unlikely.

Why then do I have to keep reapplying for my Disability Benefit every three years, Why did I have to fight and complain about wrong assessments to get my home properly adapted? Why did I have to endure condescension and dismissal by a neurologist not interested in my neurological symptoms?

Why do I have to accept psychiatrists' recommending inappropriate therapeutic techniques as "treatments"?

Why do I have to accept the denial of the WHO categorising of my neurological disease in the NICE guidelines and the promotion of a biopsychosocial psychiatrically motivated approach to my disease, when it is not a mental health illness?

Why do I have to accept a complete lack of biomedical clinics and a dearth of biomedical clinicians in dealing with my disease?

Why is there no government backing for physical research? Why are People who have vested interests in insurance companies allowed to be advisors to DWP regarding guidance in my illness?

How can the psychiatrists be allowed to define inaccurately my disease with too few symptoms and promote a vague symptom of fatigue that is not the primary dysfunction in ME? How can the psychiatric lobby get away with changing the name to CFS to ensure this wrong focus? How can the neurological nature of this illness be dismissed and people who have neurological symptoms be denied a proper service because of them? How can inappropriate therapeutic techniques be promoted by NICE when they are not wanted by people with ME as they make them more ill and disabled potentially if not actually?

Why is the ME community so divided when the issues are so clear?

People with neurological Encephalomyelitis are physically ill.

They need biomedical research and new biomedical treatments developing. They need physical research to understand the disease and develop a true identification process. They need accurate diagnostic criteria, accurate physical diagnosis and prognosis.

They need psychiatry to be placed back where it belongs which is not as a first line involvement with people with ME. They need a Benefit system and an NHS service that is not marred by vested interests. They need GP's who understand that ME is a physical illness. They need full body mapping and proper in depth tests that will show the wide range of serious dysfunction in the many different systems of their bodies. They need a full biomedical report. They need validating, supporting and valuing. They need new aids and equipment developing that can take into account their very special needs due to acute hypersensitivity.

They need easy access to benefits and aids and equipment and services. They need care staff and medical staff and anyone involved in offering an ME service to be properly trained and aware how best to work with people with such complex symptoms.

They need to be seen and heard and understood. Services need a complete change and need to be underpinned by sound biomedical research and knowledge.

If people with ME and all people who are involved with ME spoke and worked in unison we might actually start to get somewhere.

The worst thing about having ME is not the vast array of unending symptoms , that there are no drugs to alleviate, it is the isolation caused by people , both medical, official and in society including families, who do not understand this is a serious and severely disabling physical illness.

It is having to live in fear that you wont get your benefits. It is having to accept you will get wrong treatment or poor treatment or no treatment often ,.

It is knowing that you are physically ill but here is no appropriate

treatment for you and there is not going to be unless the untruth pushed by the psychiatric lobby is drowned out and shown to be false.

It is knowing that there are few clinicians if any who can actually help you. It is knowing that you have not had proper tests and that you are not going to get them even though there are tests that could be done.

It is knowing that the psychiatric lobby is downplaying this serious neurological illness and saying it is a mental health issue and no research or tests are necessary.

It is knowing that you need a proper diagnosis and medical involvement to gain the benefits , but if your GP or clinician or benefit agency doctor is psychiatrically oriented you are simply not likely to get the right help and support that you need.

It is knowing that as your neurological symptoms worsen that there are no neurologists who are willing or interested to help you locally and you are too ill to travel to see someone anyway.

It is knowing that going to hospital for tests is most likely a waste of time and energy and will lead to disappointment because they are not doing the right tests.

It is knowing that if you need drugs for some other condition they may well react badly because of your ME so you do not know if you dare take them.

It is knowing that the psychiatric promotion of the biopsychosocial approach is so successful that it is wrongly influencing doctors and nurses who may have to treat you one day and will not understand how very ill you are and will not therefore understand how to treat you properly.

It is being too ill to speak or read or write or type or fight for what is your right.

It is not knowing who to turn to for help advice support and alleviation of symptoms.

It is knowing people are being made worse by psychiatric interventions , even dying from them .

It is seeing the psychiatric lobby gain footholds in the institutions that should be supporting people with ME and knowing they are are gaining ground and power.

It is knowing that you are really ill but you have not got what you need and there is little hope of getting it.

It is understanding why people might commit suicide in this climate of disbelief and dissemination of falsehoods about the true neurological nature of ME.

We need to stand up for the name Myalgic Encephalomyelitis. We need to stand up for proper and full criteria , such as Ramsay defined or Canadian defined or hopefully even clearer more up to date but accurate criteria, to identify this specific illness. we need to stand up and demand biomedical research , biomedical input and biomedical clinician involvement.

We need to stand up for the truth of our disease.

We need to speak out the truth of this devastating physical illness and we need to be strong together.

We need to demand that the focus on fatigue be stopped and stopped now.

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