

*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 comprehensive M.E. symptom list*

COPYRIGHT © JODI BASSETT 2004. UPDATED JUNE 2012. TAKEN FROM  
WWW.HFME.ORG



It is important that the scientific facts of Myalgic Encephalomyelitis (M.E.), including an accurate picture of the symptomatology of the illness, become widely known by the media, government and the wider medical community, as well as the general public.

There is also a real need for more of this type of information to be available to the M.E. community. Despite the abundance of good research available dating back more than six decades most people with M.E. today – thanks to the politically motivated creation of the bogus disease category of ‘CFS’ in the 1980s – lack even basic accurate information about their illness.

The comprehensive M.E. symptom list has been compiled using references 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 – simply do not exist.

***This paper is divided into three categories:***

Section 1: Overview and summary

Section 2: Descriptions of individual symptoms of M.E.

Section 3: On the pattern/cause of symptom exacerbations, relapses and disease progression in M.E.

***IMPORTANT NOTES:***

1. This text is NOT a diagnostic tool and should not be used as such. Many symptoms listed are common in a variety of other disorders and it is the **pattern** of symptoms which enables a M.E. diagnosis to be made, as well as the presence of a number of **core characteristics and symptoms** which are always present in M.E., and without which a diagnosis of M.E. should never be made. (For example, damage to the brain; the CNS). There are also a number of characteristics of M.E. which are unique.

Merely having some or even many of the symptoms listed here does not mean an M.E. diagnosis is likely. Many symptoms listed are common to a large number of other diseases.

2. M.E. is a distinct, recognisable disease entity that is not difficult to diagnose and can in fact be diagnosed relatively early in the course of the disease, within just a few weeks, providing that the physician has some experience with the disease. There is just no other disease that has all the major features of M.E.

As with a wide variety of illnesses – lupus, multiple sclerosis, and ovarian cancer for example – there is as yet no *single* test which can diagnose M.E. in all patients. Therefore, like these other illnesses, M.E. must be diagnosed by taking a detailed medical history, noting the type and severity of symptomatology and other characteristics of the illness and the type of onset of the symptoms. (An acute or sudden onset of symptoms is always seen in M.E. and this onset type rules out a wide variety of other illnesses associated with gradual onset). A *series* of tests may also then be necessary to rule out or confirm a suspected M.E. diagnosis.

Objective scientific tests *are* available which can aid in the diagnosis of M.E. and easily prove the severe abnormalities across many different bodily systems seen in M.E. Unfortunately many (in fact most) patients are not given access to these tests. Problems also exist with doctors not being familiar with the abnormalities on testing seen in M.E. and so misinterpreting the results of some tests. The problem is not that these tests don't exist, but that doctors – and many patients – are unaware of this information on testing, that it is not generally accepted due to the nefarious influence of political and financial vested interest groups, and that there are overwhelming financial and political incentives for researchers to IGNORE this evidence in favour of the bogus 'CFS' (or 'subgroups of 'ME/CFS') construct. For more information on the lack of access to appropriate testing for M.E. patients see [Testing for M.E.](#)

3. M.E. patients reading this list should be aware that not all symptoms experienced may be due to M.E. and that M.E. does not mean that other illnesses – which may need urgent investigation – cannot develop.

4. To read a *personal* description of the illness see: [What it feels like to have M.E.](#)

### **Section 1: OVERVIEW - WHAT IS M.E.?**

Myalgic Encephalomyelitis (M.E.) has been recognised by the World Health Organisation since 1969 as a distinct organic neurological disease. It can occur in both epidemic and sporadic forms.

M.E. is not medically unexplained or untestable and is not the same thing as the wastebasket disease category of 'CFS' (or 'ME/CFS'). Fatigue is a symptom of many different illnesses – but it is not a defining symptom of M.E., or an essential symptom of M.E. What defines M.E. is a specific type of viral damage to the brain.

M.E. is a multi system disease which is characterised by post encephalitic damage to the brain stem; a nerve centre which controls all vital bodily functions – this is always damaged in M.E., hence the name M.E. Inconsistent CNS function is undoubtedly

both the chief cause of disability in M.E. and the most critical in the definition of the entire disease process. M.E. represents a major attack on the CNS by the chronic effects of a viral infection which targets the brain: an enterovirus.

M.E. has a sudden/acute onset that is often very dramatic. Many patients can tell you not just the day they became ill but the *hour*. M.E. is primarily neurological, but because the brain controls all vital bodily functions virtually every bodily system can be affected by M.E. M.E. is a loss of normal internal homeostasis. M.E. is secondarily a vascular disease and the vascular and cardiac dysfunctions seen in M.E. are also a major cause of much of the disability associated with M.E. More than 60 symptoms have been authentically documented in M.E.

M.E. is associated with signs and symptoms including (but not limited to):

### **Neurological signs and symptoms:**

- Inconsistent central nervous system function
- Vertigo, disequilibrium and proprioception difficulties (e.g. lack of sense of 'up' and 'down' with eyes closed)
- Temperature dysregulation and poor tolerance for hot or cold environments
- Hyperacusis (sensitivity to noise) and photophobia (pain/relapse on exposure to light)
- Pain and pressure at the back of the head (where the head meets the neck) and behind the eyes
- Blurred vision, blacked-out vision, nystagmus, wavy visual field, and other visual disturbances
- Stroke-like or coma-like episodes
- Seizures and 'sensory storms' (while conscious)
- Sleep paralysis, fragmented sleep, difficulty initiating sleep, lack of deep-stage sleep and/or a disrupted circadian rhythm
- Many other varied neurological symptoms and abnormalities

### **Vascular and cardiovascular signs and symptoms:**

- A very high heart rate, chest pressure, heart pain and a fluttering/straining heart
- Very low blood pressure particularly when upright (e.g. 84/48 or less in an adult at rest), orthostatic tachycardia/POTS and reduced circulating blood volume (up to 50%)
- Feet burning painfully and turning blue/purple on standing (Reynaud's phenomenon)
- Pain/discomfort/poor digestion following meals

### **Muscular signs and symptoms:**

- Muscle weakness and paralysis (affecting all muscles including the heart, eyes, digestive system etc.)
- Muscle pain, twitching and uncontrollable spasms

- Difficulty breathing and air-hunger, difficulty swallowing/chewing
- Paresthesias, polyneuropathy or myoclonus

### **Cognitive signs and symptoms:**

- Word-finding difficulty, scanning or disjointed speech, speech reversals, difficulty or an inability to speak
- Difficulty comprehending speech or delayed speech comprehension
- Handwriting changes, difficulty writing or comprehending text
- Difficulty with even basic mathematics (dyscalculia)
- Difficulty with simultaneous processing, concentration, spatial perception and with sequencing
- Difficulty making new memories, recalling formed memories and with immediate and delayed visual and verbal recall (e.g. facial agnosia). There is often a marked loss in verbal and performance IQ

### **Other signs and symptoms:**

- Nausea, vomiting and feeling ‘poisoned’ and very ill
- Throat and gland pain/tenderness, chills and low grade fevers
- Food allergies, alcohol intolerance, hypoglycaemia and sensitivity to common drugs/chemicals
- Ghastly pallor of face with frequent lupus-like submaxillary mask or facial vasculoid rash
- Parkinsonian rigidity of facial expression

What characterises M.E. every bit as much as the individual symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. It is unique in a number of ways and must be present for a correct diagnosis of M.E. to be made, and includes the following:

- 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.
- B. People with M.E. are limited in how physically active they can be but are also limited in similar ways with cognitive exertion, sensory input and orthostatic stress.
- C. When a person with M.E. is active beyond their individual limits, there is 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 (being upright) that is needed to cause significant relapse varies from patient to patient, but is often trivial compared to 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 time and lead to disease progression or death.
- H. The activity limits of M.E. are not short term: an increase in activity levels beyond a patient's individual limits, even if gradual, causes relapse, disease progression or death.
- I. The symptoms of M.E. do not resolve with rest. 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. 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 very severely affected patients.

30% of M.E. patients are housebound and/or bedbound and are severely limited with even basic movement and communication. Cognitive disability can be very pronounced in M.E., just as much as can physical disability.

This information is based upon an enormous body of clinical information and research. Although M.E. can cause many different symptoms the major features of epidemic and sporadic M.E. are distinct and almost identical from one patient to the next. M.E. is a severely disabling, distinct, easily recognisable and testable disease entity.

### ***More information***

- For more information about the medical and political facts of M.E. see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [What is M.E.?](#), [M.E. vs MS: Similarities and differences](#)
- For information on how to treat M.E. see: [Treating M.E. - The Basics](#). See also: [Why patients with severe M.E. are housebound and bedbound](#), [The importance of avoiding overexertion in M.E.](#) and [Hospital or carer notes for M.E.](#)

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

#### ***1. M.E. is not defined by mere 'fatigue' (or exhaustion or post-exertional fatigue or malaise)***

M.E. is not synonymous with being tired all the time. If a person is very fatigued for an extended period of time this does not mean they are having a 'bout' of M.E. Such a suggestion is no less absurd than to say that prolonged fatigue means a person is having a 'bout' of Multiple Sclerosis, Parkinson's disease or Lupus. If a person is

constantly fatigued this should not be taken to mean that they have M.E., no matter how severe or prolonged their fatigue is. M.E. and ‘CFS’ are *not* synonymous terms.

‘Fatigue’ and ‘feeling tired all the time’ are not at all the same thing as the very specific type of *paralytic muscle weakness* or *muscle fatigue* which is characteristic of M.E. (caused by mitochondrial dysfunction) and which affects every organ and cell in the body, including the brain and the heart. This causes – or significantly contributes to – such problems in M.E. as cardiac insufficiency (a type of heart failure), orthostatic intolerance or POTS (inability to maintain an upright posture), blackouts, reduced circulating blood volume (and pooling of the blood in the extremities), seizures (and other neurological phenomena), memory loss, problems chewing/swallowing, episodes of partial or total paralysis, muscle spasms/twitching, extreme pain, problems with digestion, vision disturbances, and breathing difficulties.

These problems are exacerbated by even trivial levels of physical and cognitive activity, sensory input and orthostatic stress beyond a patient’s individual limits. People with M.E. are made very ill and disabled by this problem with their cells; it affects virtually every bodily system and has also led to death in some cases. Many patients are housebound and bedbound and are often so ill that they feel they are about to die. People with M.E. would give *anything* to only be severely ‘fatigued’ or ‘tired all the time.’

Fatigue, exhaustion, post-exertional fatigue or malaise may occur in many different illnesses such as various post-viral fatigue states or syndromes, Fibromyalgia, Lyme disease, and many others, but what is happening with M.E. patients is an entirely different and unique problem of a much greater magnitude. These terms are not accurate or specific enough to describe what is happening in M.E.

Just as some M.E. sufferers will experience other non-essential symptoms such as vomiting or night sweats some of the time, but others will not, the same is true of fatigue. The diagnosis of M.E. is determined upon the presence of certain neurological, cognitive, cardiac, cardiovascular, immunological, muscular, gastrointestinal and other symptoms and characteristics – the presence or absence of mere ‘fatigue’ is irrelevant.

M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of ‘chronic fatigue’ (Hyde 2006, [Online]) (Hooper 2006, [Online]) (Hooper & Marshall 2005a, [Online]) (Hyde 2003, [Online]) (Dowsett 2001, [Online]) (Hooper et al. 2001, [Online]) (Dowsett 2000, [Online]) (Dowsett 1999a, 1999b, [Online]) (Dowsett 1996, p. 167) (Dowsett et al. 1990, pp. 285-291) (Dowsett n.d., [Online])).

## **2. What is CFS?**

CFS was created in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not exist.

All each of these flawed CFS definitions 'define' is a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue.

The disease category 'CFS' has undoubtedly been used to impose a false psychiatric paradigm of M.E. by allying it with various unrelated psychiatric fatigue states and post-viral fatigue syndromes (etc) for the benefit of various financial and political interests.

M.E. and 'CFS' are not synonymous terms. 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.*

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 at least 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 qualifies for a 'CFS' 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, sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with M.S., Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological and other M.E. symptoms. Fatigue is not a defining or even essential symptom of M.E. People with M.E. would give anything to be only '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.

There are now more than nine different definitions of ‘CFS.’ each of these flawed ‘CFS’ definitions ‘define’ a heterogeneous (mixed) population of people with various misdiagnosed psychiatric and non-psychiatric states which have little in common but the symptom of fatigue. The fact that a person qualifies for a diagnosis of ‘CFS’, based on any of the ‘CFS’ definitions: (a) does not mean that the patient has M.E., and (b) does not mean that the patient has any other distinct and specific illness named ‘CFS.’ M.E. is also not described by any of the definitions of ‘ME/CFS’ (including the Canadian ‘ME/CFS’ definition or the ICC). *Many* patients can and do fit these new wastebasket definitions that have diseases other than M.E.

The only way forward for M.E. patients and all of the diverse patient groups commonly misdiagnosed with ‘CFS’ (both of which are denied appropriate support, diagnosis and treatment, and may also be subject to serious medical abuse) is that the bogus disease category of ‘CFS’ must be abandoned. Every patient deserves the best possible opportunity for appropriate treatment for their illness and for recovery and this process must begin with a correct diagnosis if at all possible. *A correct diagnosis is half the battle won.*

- For more information on why the bogus disease category of 'CFS' must be abandoned see: [Who benefits from 'CFS' and 'ME/CFS'?](#) and [Smoke and Mirrors.](#)
- Those patients misdiagnosed with ‘CFS’ (and who do not have M.E.) are advised to read the following papers: [The Misdiagnosis of 'CFS'](#) and [Where to after a 'CFS' \(mis\)diagnosis?](#)

## **Section 2: DESCRIPTIONS OF INDIVIDUAL SYMPTOMS OF M.E.**

This list has been compiled using the highest quality resources available from the world’s leading M.E. experts, each of whom have been studying M.E. for more than 20 years and have each seen thousands of individual patients. The list also includes some signs of illness and some information on M.E. pathology. Main sources are:

- The book ‘The Clinical and Scientific Basis of Myalgic Encephalomyelitis’ edited by Dr Byron Hyde
- Papers on M.E. by Dr Byron Hyde
- Papers on M.E. by Dr Melvin Ramsay
- Papers on M.E. by Dr Elizabeth Dowsett
- Papers/lectures by Dr Paul Cheney

(Note that while some of these authors have unfortunately and unhelpfully used the (incorrect) terminology of ‘CFS’ or ‘CFIDS’ it is undoubtedly the neurological illness M.E. that has been described in each of these books and articles etc.) Note however that M.E. and ‘CFS’ are anything but synonymous terms.

Symptoms are not presented as direct quotes from these sources, and are instead paraphrased, to aid readability.

**Sections:** CARDIAC & CARDIOVASCULAR DYSFUNCTIONS; COGNITIVE & NEUROLOGICAL DYSFUNCTIONS; DIGESTIVE DYSFUNCTIONS; ENDOCRINE & NEUROENDOCRINE DYSFUNCTIONS; EXERCISE, EXERTION & PHYSICAL ACTIVITY; HEADACHES; HEARING, VESTIBULAR & SPEECH PROBLEMS; HYPOGLYCEMIA; IMMUNE SYSTEM DYSFUNCTIONS; JOINT DYSFUNCTIONS; MUSCLE DYSFUNCTIONS; ORAL DYSFUNCTIONS; PAIN; REPRODUCTIVE DYSFUNCTIONS; RESPIRATORY DYSFUNCTIONS; SEIZURES & SEIZURE ACTIVITY; SKIN, HAIR & NAILS; SLEEP DYSFUNCTIONS; URINARY TRACT DYSFUNCTIONS; VISUAL DYSFUNCTIONS; WEATHER SENSITIVITY; WEIGHT CHANGES; M.E. FATALITIES and CO-MORBID ENTITIES.

### **CARDIAC & CARDIOVASCULAR DYSFUNCTIONS**

- ❑ Reduced maximum heart rate and/or an elevated resting heart rate
- ❑ Ghastly pallor of face (usually just before or during a relapse)
- ❑ Odema (swelling of the hands and feet)
- ❑ Neurally Mediated Hypotension (NMH) low blood pressure (which causes the blood to pool in the extremities) this occurs due to an abnormal reflex interaction between the heart and the brain. This can also occur with Delayed Postural Hypotension (usually delays are around 10 minutes).
- ❑ Postural Orthostatic Tachycardia Syndrome - POTS (a heart rate increase of 30 bpm or more from the supine to the standing position within ten minutes or less) which can also occur with Delayed Postural Orthostatic Tachycardia Syndrome (usually delays are around 10 minutes). POTS in M.E. is often severe.
- ❑ Orthostatic light-headedness and/or fainting or black outs
- ❑ Very low blood pressure (hypotension) on reclining, or high blood pressure on activity. Sudden low blood pressure may cause blackouts.
- ❑ Tachycardia and an exacerbation of symptoms on orthostatic challenge (maintaining an upright posture) beyond certain limits. Lying down markedly improves symptoms for M.E. patients. *See section 3 for more information*
- ❑ Sensations of chest pain, chest pressure or fluttering sensations in the mid-chest, palpitations (skipped heart beats), tachycardia (rapid heart beat – may be 150 bpm or higher), premature atrial and ventricular contractions (early or extra heartbeats), various arrhythmias (abnormal heart rhythms), ectopic heart beats (a contraction of the heart that occurs out of its normal rhythmic pattern, it may feel like a

thumping sensation in the chest) and sleep bradycardia (a slowing of the heart rate above what is expected with sleep) can all occur.

### **COGNITIVE & NEUROLOGICAL DYSFUNCTIONS**

- ❑ A worsening of symptoms (including cognitive function) with cognitive exertion beyond a certain level. *See section 3 for more information*
- ❑ Problems with memory including; difficulty making and consolidating new memories (particularly short-term memories), difficulty recalling formed memories and difficulties with visual recall and with immediate and delayed verbal recall are common. Short-term memory problems may lead to people forgetting where they are or what they are doing, this can be so severe that patients are unable to finish a sentence. Facial agnosia may also occur (not being able to recognise faces, even those of close friends and family)
- ❑ Multi-tasking problems, an inability to learn to perform new tasks, forgetting how to perform routine tasks and a difficulty with simultaneous processing. There can be a difficulty with following step-by-step instructions, recipes or performing any tasks which require a series of separate actions. Sequencing dysfunction can also occur; inability to look words up in a dictionary, to look up phone numbers in a phone book or to organise files etc. Patients may also need extra sensory cues to complete tasks (for example, the patient may need to be able to *see* what they are doing to be able to complete a task where formerly the task could be completed using touch alone e.g. turning on a light or operating the controls in a car)
- ❑ Cognitive slowing (tasks can take much longer than usual)
- ❑ Impairment of concentration; maintaining a reasonable level of concentration on a task for even a short period of time may become extremely difficult, or impossible. There is a need for mental micro-rests.
- ❑ Difficulty with visual and aural comprehension; difficulty following oral or written directions, trouble distinguishing figure from ground and speech comprehension difficulties. Greater difficulty with auditory comprehension than visual is common.
- ❑ Word, letter and short term ordering problems, for example; transposition - reversal of letters or numbers, words or sentences when speaking or writing (pseudodyslexia)
- ❑ Inability to locate the words for writing (Agraphia). Handwriting may also change completely with the onset of illness and may be deformed in a way consistent with brain damage (this may wax and wane with the severity of the illness)
- ❑ Problems with reading (Alexia) or word blindness; patient can still read but what is read is not comprehended and cannot be compared with known information

already stored. If reading is still possible, text may have to read many times before it can be comprehended.

- ❑ Difficulty or an inability to understand speech (Wernicke's Aphasia); words are heard clearly, they are not garbled, but they make no sense. It is a loss of the ability to interpret normal language. When the input is aural, there seems to be a loss of the initial orienting information. The person is actively listening, but the information simply does not register at all or must be repeated several times before it registers
- ❑ Increased need for visual cues in understanding speech; visual or multisensorial cues are an important compensatory tool in M.E. (for example, a patient may not be able to understand the same conversation with the same person on the telephone that they understood perfectly well when conducted face-to-face).
- ❑ In speaking, important elements are often left out of the sentence such as the verb or subject, sometimes the syntax is askew. At times speech makes no sense and/or does not relate to the question asked. Sometimes speech comprehension is delayed which can result in long pauses, interruptions, mistiming of responses and apparent non sequiturs. Patients themselves may or not be aware of these problems with their speech. Incorrect word selection (paraphasia) is common, such as using the wrong word from the right category or using a word that sounds similar to the correct word but has a different meaning. Commonly used words become hard to retrieve. These problems combined may result in a significant loss of communicative ability. There can also be a difficulty pronouncing words intelligibly (Dysarthria) or a complete inability to express language (Broca's Aphasia).
- ❑ Dyscalculia; (loss of arithmetic skills) an inability or difficulty to do simple additions and other calculations, to count money, add up columns etc (irrespective of the quality of former mathematical abilities) is common. There may also be a difficulty or confusion with following timetables or keeping scheduled appointments.
- ❑ Loss of verbal and performance intelligence quotient (IQ) (A 20 point loss is average, although for some patients the loss is far more profound)
- ❑ A loss the ability to block out extraneous and unwanted information and noise; M.E. patients lose of the ability to distinguish noise from required information and tend to shut down all intake after minimal prolongation of the information signal. For example, a person may not be able to understand speech when there is more than one person speaking, more than one conversation taking place, or when there is a TV or radio on in the background. (This receptive shutdown has alarming connotations for making memories and can also at times create real danger to the M.E. patient)

- ❑ An exaggerated response to even small amounts of additional input or stimulus (light, noise, movement, vibration) is common, causing incoming messages to become scrambled or blurred resulting in distorted signals and odd sensations (ie. low level seizure activity). Even very low levels of light or noise etc. can also cause an exacerbation of other symptoms, or of the severity of the illness generally. *See section 3 for more information*
- ❑ Polyneuropathy; a neurological problem that occurs when many peripheral nerves throughout the body malfunction simultaneously. Many polyneuropathies have both motor and sensory involvement and some have autonomic dysfunction. Hyperreflexia; overactive or overresponsive reflexes eg. twitching or spastic tendencies as well as the lessening or loss of control ordinarily exerted by higher brain centres of lower neural pathways (disinhibition).
- ❑ Perceptual and sensory dysfunctions eg, spatial instability and disorientation. There may be a loss of co-ordination or clumsiness - difficulty in judging distance, placement and relative velocity (caused by proprioception dysfunctions, proprioception being the perception of stimuli relating to your own position, posture, equilibrium, or internal condition) Extension or quick rotation of the neck can cause dizziness (also due to proprioception dysfunctions)
- ❑ Altered time perception (losing time), feeling 'spaced out' or 'cloudy' or not quite real somehow
- ❑ Disorders of colour perception - recognising colours but forgetting what they mean, (Seeing the red light at an intersection, knowing it is red, but not recognising that red means 'stop,' for example)
- ❑ Abstract reasoning dysfunction; difficulty organising, integrating, and evaluating information to form conclusions or make decisions (some patients find it almost impossible to make decisions)
- ❑ Stroke-like episodes
- ❑ Short periods of amnesia may occur which may be associated with disorientation where the patient momentarily does not know where or who she is which may cause considerable anxiety. Some patients lose large parts of the day but this is infrequent. In most cases the patient can be brought out of the amnesiac attack with cues
- ❑ In severe illness patients can become unconscious, comatose for up to 23, 24 hours a day (the brain becomes unable to maintain wakefulness). There can be a difficulty in maintaining full consciousness for more than a few seconds, minutes, or half-hour periods at a time.
- ❑ Volitional problems; difficulty starting or stopping tasks, or switching from one task to another (a neurological dysfunction where the body does not respond

appropriately, or quickly, or without difficulty, to the mind's commands; is related to sleep paralysis. This is a central dysfunction and may be similar to that seen in Parkinsonianism)

- ❑ A feeling of agitated exhaustion is common (neurological in origin)
- ❑ Emotional symptoms include: mood swings (emotional lability) – crying easily, excessive irritability etc or intense emotions such as rage, terror, overwhelming grief, anxiety, depression and guilt. Sometimes there can be an emotional flattening or situations may be erroneously interpreted as novel (due to prefrontal cortex dysfunction). Disinhibition may occur to varying levels. Anxiety and panic attacks may occur, often not tied to environmental triggers. Emotional symptoms in M.E. tend to be linked to exacerbations in physical symptoms, there are often not environmental triggers. (Also note that injuries to the areas or centres of the brain which control emotions are of an identical nature as those that affect physical function; these emotional symptoms are an organic part of the illness caused by anatomical and physiological damage to the brain just as nystagmus, seizures or any other neurological problems or symptoms are. These emotional changes are also due in part to the cognitive changes caused by M.E., for example the problems with memory.)

### ***DIGESTIVE DYSFUNCTIONS***

- ❑ Oesophageal spasms (felt as extreme pain in the centre of the chest that sometimes radiates to the chest or mid-back) or oesophageal reflux (heartburn)
- ❑ Difficulty swallowing (or an inability to swallow)
- ❑ Great thirst, increased appetite, food cravings or lack of appetite
- ❑ Inability to tolerate much fat in the diet (gallbladder problems)
- ❑ Changes in taste and smell; an increased sense of smell or bizarre smells. Strange taste in mouth (bitter, metallic)
- ❑ Multiple new food allergies and intolerances
- ❑ Bloating, abdominal pain, nausea, indigestion or vomiting is common, as is diarrhoea, constipation or an alternation between the two.
- ❑ Intense gallbladder pain (in the upper right quadrant of the abdomen) or liver pain, tenderness or discomfort. Liver problems (along with other problems) can lead to a 'poisoned' feeling.
- ❑ Alcohol intolerance is common

**ENDOCRINE & NEUROENDOCRINE DYSFUNCTIONS**

- ❑ Thyroid; thyroid pain, inflammation or dysfunction (usually secondary hypothyroidism). Adrenal gland dysfunction; aspects of both overactive and underactive adrenal function or pituitary dysfunctions
- ❑ Loss of thermostatic stability - suddenly feeling cold in warm weather, recurrent feelings of feverishness or chills or hot flashes particularly involving the upper body. Feeling cold and shivering one minute and hot and sweating the next is common. A low-grade fever may occur following exertion
- ❑ Subnormal body temperature and marked diurnal fluctuation (temperature fluctuation throughout the day)
- ❑ Cold hands and feet, sometimes on only one side
- ❑ Sweating episodes (profuse sweating, sometimes even when cold) - with the sweat often having quite a sour smell. Night sweats and spontaneous day sweats may occur
- ❑ Swelling of the extremities or eyelids
- ❑ Loss of adaptability and worsening of symptoms with stress (due to endocrine dysfunctions etc.)

**EXERTION & PHYSICAL ACTIVITY**

- ❑ An exacerbation of symptoms with physical activity beyond a person's individual limits, and a worsening of the illness generally (etc.) with continued overexertion. *See section 3 for more information.*
- ❑ A sudden unexpected feeling of being 'high' can occur (due to neurological dysfunctions) leading to (usually short) bouts of physical hyperactivity
- ❑ Severe muscle weakness (paresis) or paralysis. Muscles will often function normally to start with, but pain and weakness (or paralysis) develop after short periods of use and then take 3, 4 or 5 days (or longer) to resolve (normal muscle recovery is around 200 minutes). Problems arise from *sustained* muscle use - it is a pathologically slow or impaired recovery of muscle *after* exercise. (It is a problem involving the metabolism of the muscles). Thus a patient may be easily able (for short periods) to lift something moderately heavy one or two times, but be unable to lift something very light *many* times (such as a soup spoon for example). This muscle weakness/paralysis affects all muscles/organs, including the heart, eyes and brain.

- ❑ Impaired cognitive processing, a reduced maximum heart rate, a drop in body temperature or dyspnea (shortness of breath) with overexertion. *See section 3 for more information*
- ❑ Loss of the natural antidepressant effect of exercise
- ❑ Inappropriate signs of immune system activation can be brought on by overexertion (ie. flu-like symptoms)

*See also the **CARDIAC & CARDIOVASCULAR DYSFUNCTIONS** section.*

## **HEADACHES**

- ❑ Onset of a new type, severity or pattern of headaches is common. *See also the **PAIN** section*
- ❑ Dr Hyde explains that M.E. will often cause a unique type of ‘severe headaches of a type never previously experienced.’ There is a feeling of intense pain or pressure at the base of the skull, where the skull meets the neck (occipital pain). This may also occur with neck rigidity and/or retro-orbital eye pain (pain behind the eyes) and/or blackouts or a loss of vision. This head pain is most often brought on by overexertion, particularly orthostatic. Vascular headaches such as this are well documented in M.E. from the earliest reports (for example Leon-Sotomayer) and are recorded as ‘long-term residuals’ in 100% of patients with M.E. (Thus this feature is one which may help separate M.E. patients from those with other diseases which may share some symptoms.)
- ❑ Sinus, pressure or tension headaches (dull continual headaches which are not actually caused by anxiety as the name may suggest) can occur, as can hypoglycaemia headaches (generalised prickly ache over the top of the head)

## **HEARING, VESTIBULAR & SPEECH DYSFUNCTIONS**

- ❑ Hyperacusis - an intolerance to normal sound volume and range (but particularly sounds in the higher frequencies). Sudden loud noises can also cause a startle response (flushing and a rapid heartbeat) and there can also be an extreme intolerance to vibration or movement.
- ❑ Excessive sensory inputs (noise, vibration) may lead to low level seizures and exacerbations of other symptoms . *See section 3 for more information*
- ❑ Tinnitus - ringing, buzzing, humming, clicking, popping and squeaking noises generated in the ear
- ❑ Hearing loss - sound can be muffled or indistinct or sound strangely flat, there can be a loss of tone perception

- ❑ Sharp transient ear pain, deep itching in the ears and/or swelling of the nasal passages
- ❑ Dizziness or vertigo - a sensation that your surroundings (or you) are spinning wildly (can cause vomiting). Vertigo may also be expressed in a milder form as an inability to watch TV or to read.
- ❑ Acute profound ataxia (balance problems) or a sensitivity to motion/movement (which can affect balance)
- ❑ Nystagmus - a rapid involuntary oscillation of the eyeballs
- ❑ The voice may become very weak, hoarse or fall to a whisper, and then there can be total loss of speech. There may also be a slowed rate of speech, sometimes with stammering, stuttering, muddled or slurred speech or difficulty moving the tongue to speak or getting enough air to speak more than a few words at a time.

*See also the **COGNITIVE & NEUROLOGICAL DYSFUNCTIONS** section for more information about difficulties with speech in M.E.*

### **HYPOGLYCEMIA**

- ❑ Hypoglycaemia or hypoglycaemia-like symptoms (problems with blood sugar regulation/low blood sugar)

### **IMMUNE SYSTEM DYSFUNCTIONS**

- ❑ Lymphadenopathy: lymph nodes which are tender to the touch and painful on movement. The lymph nodes in the front and back of the neck, armpits, elbows and groin are most frequently affected, particularly on the left side.
- ❑ Recurrent flu-like symptoms (general malaise, fever and chills, sweats, cough, night sweats, low grade fever, sore throat, feeling hot and having low body temperature)
- ❑ Very severe throat pain (or painful glands in the neck) scratchiness and tenderness which often worsens with exercise, exertion or before relapses. Throat may also feel clogged and require constant clearing. Throat may appear red or have characteristic ‘crimson crescents’ around the tonsillar membranes of the upper throat
- ❑ An increased susceptibility to secondary infections can be a significant problem. In addition to seasonal colds and flu patients are also more susceptible to upper respiratory tract or urinary tract infections, topical fungal infections and recurring shingles. All of these infections also last longer, can be more severe and occur more frequently and may also cause relapses either concurrently or just after the

initial infection. This is true even in cases where prior immunity has been established. *See section 3 for more information.*

- ❑ In some patients there is instead a *decreased* susceptibility to secondary infections. There is a tendency to catch either every virus going around or to 'never catch anything' depending on whether the immune system is under- or over-active (which changes dependant on which stage of the illness the person is in). Starting to get colds and flu's again can be a sign of M.E. remission or improvement
- ❑ Reactions to chemical smells: chemical sensitivities may occur to indoor and outdoor chemical air contaminants; perfumes, hairsprays, gasoline, household cleaning products, plastic and glue out-gassing. Can produce allergic reactions although not all chemical sensitivities are IgE mediated. May also cause an exacerbation of other symptoms. *See section 3 for more information*
- ❑ New sensitivities may also occur to some drugs and medications (particularly those which act on the CNS)
- ❑ Worsening of existing allergies and/or new severe sensitivities/allergies/intolerances to many varieties of food (and food additives) and to airborne allergens: pollen, mould, animal dander, fur and feathers or dust.

### **Allergy symptoms:**

- Skin: pallor, itching, burning, tingling, flushing, warmth or coldness, sweating behind the neck, hives, blisters, blotches, red spots, pimples, dermatitis, eczema
- Eyes: blurred vision, itching, pain, watering, eyelid twitching, redness of inner angle of lower lid, drooping or swollen eyelids
- Ears: earache, recurring ear infections, dizziness, tinnitus, imbalance
- Nose: nasal discharge or congestion sneezing
- Mouth: dry mouth, increased salivation, stinging tongue, itching palate, toothache
- Throat: tickling or clearing, difficulty swallowing
- Lungs: shortness of breath, air hunger, wheezing, cough, mucous or recurrent bronchial infections
- Heart: pounding or skipped heartbeats, chest tightness
- Gastrointestinal tract: burping, heartburn, indigestion, nausea, vomiting, abdominal pain, gas, cramping, diarrhoea, constipation, mucus in stool; frequent, urgent or painful urination, bedwetting (in children)
- Muscular system: muscle fatigue, weakness, pain, stiffness, soreness
- Central nervous system: headache, migraine, vertigo, drowsiness, sluggishness, giddiness
- Cognition: lack of concentration, feeling of 'separateness', forgetting words or names, anxiety, tension, panic, overactivity, restlessness, jitteriness, depression, PMS

**JOINT DYSFUNCTIONS**

- ❑ Significant myalgia (pain) in joints is often widespread. The most common joints affected are knees, ankles, elbows, hips but pain in the fingers also occurs. Aching in the joints is also common
- ❑ Gelling (stiffness) in the joints that develops after holding a position for awhile, usually sitting or upon awakening but can also be caused by changes in temperature or humidity
- ❑ Gait abnormalities and a difficulty with tandem gait

**MUSCLE DYSFUNCTIONS**

- ❑ Significant myalgia in muscles is often widespread (sharp, shooting, burning or aching pain). Pain can be extremely severe in M.E. *See also the PAIN section*
- ❑ Transient tingling, numbness and/or burning sensations (or other odd sensations) in the face or extremities (paresthisias).
- ❑ There is sometimes atrophy of specific muscle groups (a shrinking in size visible to the eye)
- ❑ Inability to form facial expressions leading to a 'slack' facial appearance
- ❑ A loss of the ability to chew or swallow
- ❑ Severe muscle weakness (paresis) or paralysis. Muscles will often function normally to start with, but pain and weakness (or paralysis) develop acutely after short periods of use and then take 3, 4 or 5 days (or longer) to resolve (normal muscle recovery is around 200 minutes). Problems arise from *sustained* muscle use - it is a pathologically slow or impaired recovery of muscle *after* exercise. (It is a problem involving the metabolism of the muscles). Thus a patient may be easily able (for short periods) to lift something moderately heavy one or two times, but be unable to lift something very light *many* times (such as a soup spoon for example). This muscle weakness/paralysis affects all muscles/organs, including the heart, eyes and brain.
- ❑ Visible tremors and twitches of the muscles (involuntary movements)
- ❑ Muscle spasms, which can be extremely severe and painful. There may be spasms of the hands and feet which can lead to 'clawed' deformities or spasms in the neck which cause the head to twist to one side
- ❑ Slight hesitation in movement or 'cogwheel' effect with movement

## **ORAL DYSFUNCTIONS**

- Dental decay and periodontal disease (gum disease) are much more common than in the general population
- Frequent canker sores (painful sores in the mouth which look like small bumps with white heads)
- Loose teeth and endodontal (the soft tissue in the centre of the tooth) problems
- Temperature sensitivity in the teeth and/or pain in the teeth

## **PAIN**

- Three different types of muscle pain in M.E.:
  1. Patient complains of feeling as though they have been beaten repeatedly with an axe handle; bruised and hurt all over. Is sometimes associated with a dull headache and an inability to concentrate.
  2. Severe spike-like pain, usually in the main muscle mass in the leg; extensors or flexors. It is commonly described as feeling as though a nail or a knife had been stuck into the area.
  3. Occurs after a particular muscle group has been in use for an extended period; the affected muscles become weak/paralysed and painful and this takes 3-5 days (or longer) to resolve. The affected muscle can frequently be palpated and is hard and swollen.
- Cephalgias and other head area pain: encephalitic pain, pain behind the eyes, expanding head pain, ear pain, ophthalmic pain, tooth-hypersensitivity pain, spike-like pain, fibromyalgia pain, formication, sore throat and very sore glands in the neck (and possibly elsewhere) on one or both sides (particularly after overexertion) and spasm associated pain
- Other types of pain: chest and abdominal pain, causalgia and other neuralgic pain, abdominal pain, urogenital pain, pain in the extremities (hypothalamic dysfunction pain, periarticular pain, bone pain and muscle pain)
- Pain reception impairment: skin is very sensitive to the touch and there can be also be allodynia - a pain response to stimuli not usually painful (some patients find the weight of their sheets becomes extremely painful and intolerable, for example)

## **REPRODUCTIVE DYSFUNCTIONS**

- Menstrual cycles may become shorter, longer or irregular. Periods may also become lighter or disappear altogether (usually when illness is severe) There may also be an intensification of M.E. symptoms before and during a period

- ❑ Lowered libido
- ❑ Impotence

### **RESPIRATORY DYSFUNCTIONS**

- ❑ Erratic breathing pattern
- ❑ Dyspnea - air hunger or difficulty breathing (often on waking or with exertion), which can be severe. *See section 3 for more information*
- ❑ Persistent coughing and wheezing

### **SEIZURES & SEIZURE ACTIVITY**

- ❑ Grand mal seizures (where there is loss of consciousness and motor dysfunctions),
- ❑ Petit Mal seizures - absence seizures (where you are conscious but unaware of your actions. A person may continue with an activity as though asleep – an ambulatory automatism may occur)
- ❑ Simple partial seizures - do not involve loss of consciousness but produce altered sensations, perception, mood or bodily sensations; somatosensory seizures, autonomic seizures, focal motor seizures, auditory seizures, visual seizures. Complex partial seizures: episodic dysphasia/dyspagia (incomprehension of speech and inability to speak), olfactory hallucinations. Other seizures: tremulous attacks and psychomotor attacks. (Dr Byron Hyde states in his M.E. textbook that by definition *all* M.E. patients will have some level of seizure activity as part of their illness.)
- ❑ Sensory storms/overload phenomena or a worsening of symptoms generally caused by a hypersensitivity to light, sound, vibration, movement, temperature, odours and/or mixed sensory modalities. *See section 3 for more information*
- ❑ Myoclonus (strong involuntary jerks of the arms, legs or entire body)

### **SKIN, HAIR & NAILS**

- ❑ Rashes, dry and peeling skin, acne, spontaneous bruising, fungal infections, butterfly rash on face, flushing of face and ghastly pallor of face
- ❑ Destruction of fingerprints is sometimes seen (atrophy of fingerprints is due to perilymphocytic vasculitis and vacuolisation of fibroblasts) and the skin on the fingertips may become then, red and shiny.
- ❑ Vasculitic skin lesions are documented in M.E. A Lupus-like submaxillary mask on the face or a facial vasculoid rash, are common.

- ❑ Hair loss and poor quality regrowth.
- ❑ Nails may have vertical ridges, bluish nail bed, brittleness and be prone to fungal infections

### **SLEEP DYSFUNCTIONS**

- ❑ Disrupted, chaotic or reversed circadian (sleep and wake cycle) rhythms
- ❑ Difficulty initiating sleep, maintaining sleep (fragmented sleep) or hyposomnia (lack of sleep) may occur
- ❑ Hypersomnia - excessive sleeping (common in the acute stages of the illness, a rare feature thereafter. Is more common in children than adults and thought to be most often caused by a dysfunction in the posterior hypothalamus and the upper part of the mid-brain.)
- ❑ Very light sleep (lack of deep stage sleep)
- ❑ Dreaming changes: intensely colourful and bright dreams (vivid), violent and attacking nature of dreams (nightmares), frequency of hypnagogic and hypnapagogic dream states (waking dreams, thematic dreams, pain dreams and sleep paralysis) and increased dreaming activity (thought to be caused by sensory seizures in the midbrain). There is also sometimes a complete lack of dreams.
- ❑ Sleep paralysis: temporary paralysis after sleeping (also called waking paralysis, can last from minutes to hours), early waking states (where you are neither asleep nor awake which can last for minutes or many hours) or dysania can occur
- ❑ Night extremity hypothermia

### **URINARY TRACT DYSFUNCTIONS**

- ❑ Urinary frequency and bladder dysfunction, uncomfortable or painful/burning urination (Dysuria), difficulty passing urine, incontinence and/or nocturia (excessive urinating at night)

### **VISUAL DYSFUNCTIONS**

- ❑ External visual dysfunctions: photophobia (extreme sensitivity to light), oscillating or diminished pupillary accommodation responses with retention of reaction to light, nystagmus (a rapid involuntary oscillation of the eyeballs), painful or burning sensations in the eyes, floaters, spots and scratchiness in vision, tearing and dry eye, internal and external ophthalmoplegia (paralysis of the extraocular muscles which are responsible for eye movements) changes in colour vision, sluggish focus, an inability to focus or accommodation difficulty

(difficulty switching from one focus to another) can all occur as can double, tunnel, wavy or blurred vision, or night blindness.

- ❑ Central visual dysfunctions: visual comprehension dysfunction, reading ability loss or difficulty, writing ability loss or difficulty, distance or spatial dysfunction, loss of depth of field – less ability to make figure/ground distinctions, vision reversals and vision clouding. *See also the **COGNITIVE & NEUROLOGICAL DYSFUNCTIONS** section for more on difficulties with reading and writing*

### **WEATHER SENSITIVITY**

- ❑ Intolerance of extremes of hot and cold weather. Periods of extended hot weather in particular are seldom well tolerated by M.E. patients. Hot (or even warm) weather often causes a severe worsening of the base level of illness and of many different symptoms (particularly cognitive problems in many cases).
- ❑ Insomnia, migraines, irritability or generally ‘feeling off’ a day or two before the weather changes. Changes in temperature or humidity can cause stiffness or increased aching or pain in the muscles. Changes in barometric pressure can cause night sweats and spontaneous sweating during the day

### **WEIGHT CHANGES**

- ❑ Marked weight gain (often independent of dietary changes)
- ❑ Marked weight loss (often independent of dietary changes). Rapid weight loss can also occur despite large quantities of food being eaten. (Weight loss independent of dietary changes seems to be more common amongst younger sufferers, particularly children and teenagers.)

---

**M.E. FATALITIES:** Most deaths from M.E. (around two thirds) are due to organ failure, usually cardiac or pancreatic. Death can also occur as a result of secondary infections or problems with maintaining breathing. See THE LATE EFFECTS OF ME by Dr Elizabeth Dowsett for more information. See also: The Severity of M.E. and M.E. Fatalities.

**CO-MORBID ENTITIES:** (Note that some conditions, such as POTS for example, are instead included in the general symptoms list because they are so central to M.E.)

- Increased tendency for Mitral Valve Prolapse, especially in children (breathlessness, fatigue, edema)
- Viral myocarditis - inflammation of the heart (usually of little consequence but which can sometimes lead to substantial cardiac damage and severe acute heart

failure. It can also evolve into the progressive syndrome of chronic heart failure. There have been sudden deaths associated with exceptional physical exertion in patients with viral illnesses)

- Pericarditis (the outer layer of the heart, pericardium, is inflamed. Symptoms include chest pain, shortness of breath, and rapid, shallow respiration)
- Secondary or reactive depression (as with any other debilitating chronic illness)
- Irritable Bowel Syndrome
- Raynaud's phenomenon
- Shingles
- Systemic yeast/fungal infections
- Multiple Chemical Sensitivity Syndrome MCSS
- Carpal tunnel syndrome (weakness, pain, and disturbances of sensation in the hand)
- Piriform muscle syndrome causing sciatica
- Positive Fibromyalgia tender points (FMS) and Myofascial trigger points (MPS) are common
- Temporomandibular Joint Syndrome TMJ (spasms of the jaw muscles causing intense pain)
- Hashimoto's thyroiditis
- Sicca Syndrome
- Endometriosis (the presence and growth of functioning endometrial tissue in places other than the uterus that often results in severe pain and infertility) may be more common in M.E.
- Dysmenorrhoea - menstrual pain experienced a week before, during and a few days after periods (other symptoms include; headache, suprapubic cramping, backache, pain radiating down to anterior thigh, nausea and vomiting, diarrhea, syncope)
- More severe or new onset PMS
- Migraines (nausea, vomiting, head pain, light and noise sensitivity which can last for hours or days)
- Restless Legs Syndrome RLS
- Sleep apnea
- Irritable Bladder Syndrome
- Cystitis (inflammation of the urinary bladder)
- Prostatitis (inflammation of the prostate gland)
- Sjogrens syndrome (autoimmune disorder affecting moisture producing glands in the body)

### ***Section 3: ON THE PATTERN/CAUSE OF SYMPTOM EXACERBATIONS, RELAPSES, AND DISEASE PROGRESSION IN M.E.***

What characterises M.E. every bit as much as the individual symptoms is the way in which people with M.E. respond to physical and cognitive activity, sensory input and orthostatic stress, and so on. It is unique in a number of ways and along with CNS

damage must be present for a correct diagnosis of M.E. to be made, and includes the following:

- 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.
- B. People with M.E. are limited in how physically active they can be but are also limited in similar ways with cognitive exertion, sensory input and orthostatic stress.
- C. When a person with M.E. is active beyond their individual limits, there is 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 (being upright) that is needed to cause significant relapse varies from patient to patient, but is often trivial compared to 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 time and lead to disease progression or death.
- H. The activity limits of M.E. are not short term: an increase in activity levels beyond a patient's individual limits, even if gradual, causes relapse, disease progression or death.
- I. The symptoms of M.E. do not resolve with rest. 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. 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 very severely affected patients.

***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.***

Only being able to achieve 50% or less of your pre-illness activity level immediately upon becoming ill is very common – if not universal – in Myalgic Encephalomyelitis. (Although a small percentage of sufferers may possibly be somewhat less severely affected at onset.) This is not a gradual change in ability levels which occurs over weeks, months or years; it is an acute change. The onset of M.E. is frequently very

dramatic, M.E. patients can very often tell you not just the day that they became ill, but the exact *hour* they became ill.

- M.E. can commonly be diagnosed within just a few weeks if the doctor has experience with M.E. For more information on the viral infection evident at onset in people with M.E., and the outbreaks of M.E. etc. see: [The outbreaks \(and infectious nature\) of M.E.](#)
- M.E. is an acute onset illness, however it should be noted that: (a) some sufferers will be unsure of their onset type (they may not recall it, or may not recall it accurately, for various reasons) and (b) in some cases, acute onset M.E. is preceded by a series of unrelated minor infectious episodes (in a previously well patient) which may be misinterpreted as being a gradual onset of the M.E. (These minor infectious episodes may be due to the immune system being under temporary or chronic stress from events such as; recent immunisation, repetitive contact with a large number of infectious persons, or the effect of travel; as in exposure to a new subset of virulent infections. This pre-existing temporary or chronic immune system weakness is not seen in all patients and is *not* what causes M.E., although a compromised immune system will of course make the body more vulnerable to all types of infections, including M.E.)

***B. People with M.E. are limited in how physically active they can be but are also limited in similar ways with cognitive exertion, sensory input and orthostatic stress.***

The bodies of people with M.E. respond inappropriately to anything that forces the body to have to react in some way or work harder in some way. This includes (but is not limited to): physical activity, cognitive exertion (including emotional stress), sensory input and orthostatic stress. It should also not be assumed that a person with M.E. will necessarily react more severely to (or have greater limits on) physical activity than with cognitive exertion, sensory input or orthostatic stress. Some patients find that their most severe relapses come from orthostatic stress, while others will have to be more careful with their levels of sensory input or cognitive exertion as compared to physical activity. Other patients may be equally limited with each of these activities or stimuli, and so on. It varies from patient to patient and can also change over the course of the illness.

One of the main misconceptions about M.E. is that while walking a few steps must of course require additional bodily resources and additional cardiac output, time spent thinking, looking, listening or experiencing other sensory stimuli does not. But this is not the case. Not only physical effort, but also cognitive effort, requires additional resources which an M.E. patient may not have. The brain contains some 100 billion neurons connected to some 10,000 relay stations and this enormous electrical activity creates a massive need for energy and other bodily resources. The brain uses up to 25% of the entire body's demand for glucose, 25% of the blood pumped from the heart goes to the brain and the brain also needs 25% of the body's oxygen supply. (Blood supplies nutrients like glucose, protein, trace elements, and oxygen to the

brain.) So of course, every extra second of ‘electrical activity’ – every thought, every feeling, every noise heard or sight seen – requires additional cardiac output, makes additional oxygen and glucose demands, and so on, in just the same way as does a physical activity such as walking; if not more so.

- *What is Homeostasis?* Homeostasis is the ability of a living organism to regulate its internal environment to maintain a stable, constant condition, by means of multiple dynamic equilibrium adjustments, controlled by interrelated self-regulation mechanisms. Homeostasis is one of the fundamental characteristics of living things. It is the maintenance of the internal environment within tolerable limits. M.E. causes a loss of the ability of the CNS (the brain) to adequately receive, interpret, store and recover information which would enable it to control vital body functions. There is a loss of normal internal homeostasis; the individual can no longer function systemically within normal limits.

Metabolic problems at a cellular level also contribute to this inability to maintain homeostasis in M.E. M.E. expert Dr Byron Hyde explains, ‘In MRI spectography of arm muscle of M.E. patients, it has been shown that because of an abnormal build-up of normal metabolites, the muscle cell actually shuts down to prevent cell death.’ This is what is happening to the M.E. patient’s cell physiology in every muscle (including the heart) and in the brain as a result of physical and cognitive activity and/or overexertion; there is ‘cell field shutdown’ to prevent the death of the cell. See: Treating M.E. for more information and for references.

- Physical activity in this context does not just mean aerobic exercise; it includes any physical movement or activity, including stretching and even very small movements. Cognitive activity refers to any type of thinking, or mental processing. Sensory input includes exposure to light, noise and movement etc. Orthostatic stress or postural stress includes sitting or standing, but also things like having a few pillows under your head when lying down or sitting up in bed; orthostatic stress is caused by any posture other than lying down flat (perhaps with legs raised to reduce the load on the heart; unless the patient is wearing pressure stockings, which achieve the same goal.).

***C. When a person with M.E. is active beyond their individual limits, there is a worsening of various neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms.***

When a person with M.E. is active beyond their individual post-illness limits, the result is not tiredness, fatigue or even exhaustion – nor is ‘malaise’ an accurate word to describe what occurs. There simply is no one symptom caused by overexertion in M.E. What does happen is that there is a worsening of all sorts of different symptoms and of the severity of the illness generally with overexertion. (Repeated or severe overexertion can also cause disease progression, permanent damage (eg. to the heart), or death in M.E.) It is an entirely different problem of a much greater magnitude.

Overexertion causes an exacerbation of all sorts of combinations of neurological, cognitive, cardiac, cardiovascular, immunological, endocrinological, respiratory, hormonal, muscular, gastrointestinal and other symptoms which can be mild, moderate, severe, or even life threatening (eg. seizures and cardiac events). Many of the symptoms involved are present at a lower level at rest, but overexertion causes them to worsen. (Although some patients may also have some symptoms that only appear after overexertion.)

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

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

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

- A large number of illnesses cause significant fatigue or malaise after activity (for example post-mononucleosis or glandular fever fatigue syndromes, Lyme disease and Fibromyalgia and so on) but what is happening in M.E. is simply not the same; the symptomatology and pathology – and the effect of physical, cognitive and orthostatic overexertion on long-term prognosis – is very different in M.E.
- *An additional note on ‘fatigue’*: The symptom of fatigue is not an essential symptom of M.E. and does not define M.E. (although the symptom of fatigue *is* essential to qualify for a misdiagnosis of ‘CFS’). For more information see: [The misdiagnosis of CFS](#). The point to be most aware of is not that M.E. is ‘more than fatigue’ – but that M.E. *ISN’T FATIGUE AT ALL*.

***D. The level of physical activity, cognitive exertion, sensory input or orthostatic stress (being upright) that is needed to cause significant relapse varies from patient to patient, but is often trivial compared to pre-illness tolerances and abilities.***

When there is talk of ‘overexertion’ leading to an exacerbation of symptoms in M.E. what is being referred to is not hard exercise, it is not anything resembling what healthy people would recognise as ‘overexertion.’ This term just refers to any activity which goes beyond a person’s individual post-M.E. limits.

There is a lot of variation from patient to patient but very often the levels of activity required to cause relapse are trivial compared to a patient’s pre-illness tolerances and abilities. For example, what constitutes overexertion for someone with severe M.E. could be something as small as rolling over in bed, walking or talking for a few minutes, or eating a meal. The severity and duration of relapses varies depending on the severity of a person’s illness, but relapses in M.E. are very often way out of all proportion to the actual activity. Relapses can be very severe and prolonged (or even permanent) even if a person with M.E. has only gone past their individual limits in a seemingly minor way.

- *A note on M.E. and other illnesses*: This extreme and out of all proportion reaction to even trivial levels of activity is just not seen in those illnesses causing fatigue (and other symptoms) after exertion which may commonly be misdiagnosed as ‘CFS.’ People with post-viral fatigue syndromes, Fibromyalgia and Lyme disease etc. are not affected by small activities for many weeks, months, or permanently, in this way.

***E. The severity of M.E. waxes and wanes throughout the hour/day/week and month.***

One can probably observe people with some illnesses carefully for an hour or so and collect a lot of good information about what they can and can’t do, how severe their illness is, and what their usual symptoms are from day to day, and so on. However M.E. is not one of those illnesses. M.E. is *not* a stable illness.

Observing the average M.E. sufferer for an hour – or even a week or more – will not give an accurate indication of their usual activity level because the severity of M.E. can wax and wane throughout the month, week, day and even hour. Also, people with M.E. can sometimes operate significantly above their actual illness level for short periods of time thanks to surges of adrenaline – albeit at the cost of severe and prolonged worsening of the illness afterward. Relapses and worsening of symptoms are also very often also significantly delayed (there may be both an acute AND a delayed reaction).

Just observing someone with M.E. do a certain task should not be taken to mean (a) that they can necessarily repeat the task anytime soon, (b) that they would have been able to do it at any other time of day, (c) that they can do the same task every hour, day or even every week, or month, or (d) that they won't be made very ill afterwards for a considerable period because they had to really push themselves (and make themselves ill) to do the task.

Often a considerable rest period is needed before and after a task, which may be hours, days, weeks or months long. For example, someone may need 2 weeks rest before an outing, for example, and may then spend 3 weeks extremely ill afterwards recovering from it. Just observing them in the 2 hours they were 'out and about and mobile' is of course not at all representative of their usual ability levels.)

Most importantly, because the worsening of the illness caused by overexertion may not even begin until 48 or more hours afterwards (when most observers are long gone), it's impossible to tell by seeing an M.E. patient engaged in an activity, whether that activity is so far beyond the patient's limits that it will end up causing a severe or even permanent worsening of the illness (or 'relapse'). To be blunt, the activity may even end up killing the patient. This isn't common (the death rate is estimated at 3%), but deaths can and do occur. Thus, observers who see an M.E. patient engaged in an activity have no idea what the consequences of this activity may be.

- What is an adrenaline surge? Adrenaline is often referred to as the 'fight or flight' hormone as it kicks into action in situations of potential danger. However, adrenaline also kicks in when the body is in physiological difficulty, which is very often what is happening to severe M.E. sufferers. Adrenaline surges make the heart pump faster and raise the blood pressure, forcing blood around the body with greater force to supply the muscles with more oxygen, so that they can make a greater effort. Surges of adrenaline increase the metabolism. They also relax and dilate the airways so that more oxygen than usual can be taken in. Adrenaline surges can also decrease the amount of pain felt. As a result of all of these factors, adrenaline surges – while they last – have the ability to increase physical speed, strength and other physical abilities.

Unfortunately, when these bursts of adrenaline wear off – as they must – people with M.E. are left far more ill as a result for many days, weeks, months or even years. People with M.E. are harmed by adrenaline surges, both by the physiological stress to the body of the changes caused by adrenaline, and by the

extra activity which adrenaline enables, which may be far beyond the body's normal limits so that such activity causes damage. For every short term 'gain' there is a far greater loss overall. For more information on adrenaline surges in M.E. see: [Assisting the M.E. patient in managing relapses and adrenaline surges](#)

- *A note on M.E. and other illnesses:* This is another one of the characteristics which clearly differentiates authentic M.E. from various self-limiting post-viral fatigue syndromes and so on – the striking variability of symptoms not only in the course of a day but often within the hour. As many M.E. experts have noted, this variability of the intensity of the symptoms is simply not found in post-viral fatigue states or syndromes (etc). There is also a waxing and waning of the *physical signs* of M.E. throughout the day, as [Dr Hyde](#) and [Dr Jain](#) explain, “A patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day.”

***F. The worsening of the illness caused by overexertion often does not peak until 24 - 72 hours or more later.***

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

The onset of the worsening of symptoms caused by overexertion is sometimes be acute but often will not peak until 48 hours or more afterward (this is particularly true with regard to physical, cognitive and orthostatic exertions). Symptoms will then persist for hours, weeks or many months, or longer. For many M.E. sufferers, the effects from significant overexertion will very often peak on day three.

Sometimes there is a significant worsening of symptoms evident at the time of overexertion. At other times, there may only be a minor worsening of symptoms at the time of overexertion, but the delayed effects will be severe. Sometimes the acute effects and the delayed effects will both be severe. It varies depending on the type and severity of the overexertion involved etc.

- *A note on M.E. and other illnesses:* The ‘CFS’ definitions state that post-exertional symptoms ‘may take up to 24 hours to resolve.’ But to say that this is true of M.E. patients betrays an ignorance of the most basic facts of M.E. Post-exertional symptoms very often take far longer than 24 hours to even APPEAR in people with M.E., let alone be completely resolved in that time. These symptoms can take days, weeks, months or even several years to resolve. Overexertion can also cause a worsening of the base level of illness in M.E. and so the effects of overexertion can also be semi-permanent or permanent. Death can also occur due to overexertion in M.E.

### ***G. The effects of overexertion can accumulate over time and lead to disease progression, or death.***

In addition to the effects of overexertion commonly being delayed by 48 hours or so, the worsening of symptoms caused by overexertion can also sometimes be delayed (and accumulate) over weeks or even many months at a time until they are realised in a ‘crash.’ This is a period of intense worsening of the overall condition followed by a gradual return to the patient’s base level of illness over weeks, months or even years.

When the body is confronted with activity (or inputs) beyond the patient’s individual limits severely and/or repeatedly over time, these effects can also become cumulative in the long term; the patient becomes unable to return to their base level of illness at all. What this means is that long-term or permanent worsening of the overall severity of the condition is caused. Thus some patients are still dealing with the severe physical effects of inappropriate advice to exercise or to be more physically or mentally active etc. five, ten, fifteen or more YEARS afterward and for some patients the damage caused is permanent. Overexertion has also resulted in death in some cases of M.E.

Strong evidence exists to show that overexertion can have extremely harmful effects on M.E. patients. 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. (Recent research has shown that postural stress and physical and mental overexertion exacerbate cardiac insufficiency in this disease; see the notes below for more information.) In addition to the risk of relapse, permanent damage, and disease progression, there have also been reports of sudden deaths in M.E. patients following exercise. As M.E. expert Dr. Elizabeth Dowsett explains, ‘20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led to sudden death following exercise. Prompt recognition and advice to avoid over-exertion is mandatory.’

- For more information on the question of “*Can M.E. patients really die just from being forced out of bed, or to leave the house etc.?*’ please see the paper: Why patients with severe M.E. are housebound and bedbound
- Cardiac and vascular abnormalities have been documented from the earliest outbreaks of M.E. to the present day. Dr. Paul Cheney explains that when M.E. patients stand up, they are on the edge of organ failure as their cardiac output has dropped to the extremely low level of 3.7 litres per minute, a 50% drop from the normal output of 7 litres per minute. Without exception, says Cheney, every M.E. patient ‘is in heart failure.’

Recent research shows that mitochondrial and other dysfunction leads to diastolic dysfunction and reduced stroke volume/low cardiac output in M.E. – and that certain levels of orthostatic stress and physical and mental activity etc. exacerbate this cardiac insufficiency. Dr Cheney explained recently that because it takes more metabolic energy for the heart to relax and fill with blood than it does

for it to squeeze and pump blood, the hearts of people with M.E. don't fill with the proper amount of blood before they pump which is what causes the reduced cardiac output and many of the symptoms of M.E. (and much of the disability of M.E.). So the tachycardia – fast heart rate – often seen in M.E. in response to orthostatic stress and so on is actually compensating for low stroke volume to help increase cardiac output. The heart doesn't fill with enough blood before each beat of the heart so it is forced to beat faster to try to make up some of the shortfall, but people with M.E. are still left with reduced cardiac output which leaves them very ill and disabled. If this problem is severe enough it can result in death.

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

***H. The activity limits of M.E. are not short term: an increase in activity levels beyond a patient's individual limits, even if gradual, causes relapse, disease progression or death.***

Increasing the activity levels of someone with M.E. beyond their individual limits, can only ever be counterproductive. It really doesn't matter if you do this gradually or all at once. Raising the limits gradually may well delay the onset of the relapse in some patients, but the end result will still be relapse and/or disease progression, or death. None of the various cardiac, cardiovascular, immunological, neurological, cognitive, muscular, and other abnormalities present in M.E. sufferers – which together cause the high level of disability associated with M.E. – can be explained by mere 'deconditioning.' *Patients who improve with graded activity programs do not qualify for a diagnosis of M.E.*

- M.E. is a chronic illness which affects the vast majority of sufferers for many years or decades at a time, or for the rest of their lives. A person who has been correctly diagnosed with M.E. will naturally raise their activity levels when/if they have had an improvement in their illness – but it can never work the other way around. See: [Smoke and mirrors](#) for more information.
- *A note on M.E. and other illnesses:* M.E. can be progressive, degenerative, chronic, or relapsing and remitting. As many M.E. experts have noted, the

chronicity of M.E. is another characteristic which clearly separates the illness from various self-limiting post-viral fatigue syndromes.

***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.***

There is a base level of illness that is always present in M.E., even at rest. (This is true of all sufferers except perhaps that small percentage who have improved enough over time to be only mildly affected, or who have had a total or almost total remission of their M.E.) This is because the metabolic problems of M.E. are only one part of M.E., they are not the only cause of symptoms or of the worsening of the illness.

But even those symptoms which are caused by the metabolic problems of M.E. (etc.) do not always resolve with rest. For severely affected patients, just keeping the body going at the lowest possible level can count as ‘overexertion’ – not only can the bodies of these people not cope with extra activity, but they also cannot even cope with keeping the bodily systems and organs going at the lowest possible level – at rest. Because even when we are resting as much as we can be; hearts have to keep pumping, lungs have to keep drawing air in and out constantly, kidneys have to keep working, and so on. It takes a lot of metabolic power to keep all the complex systems in the body working, even at the lowest possible level. Forcing the body to do more work when it is already not coping with the most basic level of functioning causes these problems to become even more severe as the quality of function achieved across various bodily systems is lowered even further, but even at rest these same problems can be quite severe because of course so many different bodily systems never can ‘rest.’

Virtually all bodily systems are affected in some way by both the damage to the central nervous system and the metabolic problems of M.E. (including the cardiac insufficiency this causes) etc. so it is no wonder people with M.E. feel so ill, have such a reduced level of functioning in so many different bodily systems and have so many restrictions and limits on how active they can be. Even with complete rest – and some people with M.E. can do almost nothing else – many M.E. sufferers are still very ill and disabled.

***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.***

It is vital that M.E. patients are never encouraged to be active beyond their individual limits. As Dr Melvin Ramsay explains;

The degree of physical incapacity varies greatly, but the [level of severity] is directly related to the length of time the patient persists in physical effort after its onset; put in another way, *those patients who are given a period of enforced rest from the onset have the best prognosis*. Since the limitations which the disease imposes vary considerably from case to case, the responsibility for determining these rests upon the patient. Once these are ascertained the patient is advised to fashion a pattern of living that comes well within them.

Patients with M.E. must be allowed to determine for themselves a level of daily activity which is not needlessly restrictive, but which is also sustainable in the long term without causing a worsening of symptoms or disease progression (and which also holds back a small amount of ability to cope with occasional unplanned or unavoidable overexertions, to prevent these from causing significant setbacks). People with M.E. must also be allowed to determine for themselves how much rest they need.

Giving people with M.E. the support they need to limit their activities in this way is actually the best way to ensure that they each get to be as active as possible in the long term. The importance of getting appropriate rest and avoiding overexertion in M.E. cannot be overstated. Forcing or encouraging people with M.E. to engage in even low levels of physical and cognitive activity, sensory input and orthostatic stress beyond their individual limits can have catastrophic long-term consequences.

- For more information about the effects of overexertion on M.E. patients, including statements/research from some of the world's leading M.E. experts about why overexertion is so physically harmful, see: [Smoke and Mirrors](#).

***L. 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 very severely affected M.E. sufferers there is virtually no 'safe' level of physical or mental activity, orthostatic stress or sensory input; no level which does not produce a worsening of symptoms, and perhaps also contribute to disease progression. Even the most basic actions – speaking a few words, being exposed to moderate light or noise for a few minutes, turning over in bed, having hair or body washed in bed by a carer or chewing and swallowing food – cause severe and extended symptom exacerbations in such patients. It is not uncommon to hear of very severely affected sufferers who are unable to bathe themselves (or even be bathed by a carer) more often than once a week, or even once every few weeks, or even less. Some sufferers cannot chew or swallow food any longer and need to be tube fed. Many patients with severe M.E. are no longer able to toilet themselves, and so on. Either sufferers are just too ill to do these things at all, or they cannot tolerate the very long and severe relapses that come after such activities.

Even the smallest movement, thought, touch, light, noise or period upright etc. can the already very severe symptoms far, far worse. Thus few illnesses demand such isolation and loss of quality of life as severe M.E. Very often people with very severe M.E. can barely communicate, or even tolerate the presence of another person. This is what makes M.E. such a cruel disease and such an isolating disease. The illness can cause a level of disability and isolation that is just unimaginable to anyone not familiar with very severe M.E.

- For more information on severe M.E. see [The severity of M.E.](#) plus [Why patients with severe M.E. are housebound and bedbound.](#)

### ***SYMPTOM LIST REFERENCES (and recommended additional reading list)***

All symptoms/signs are taken from the following references. (Any categorisation errors are mine alone however. Many – almost all – symptoms fit into more than one sub-heading).

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.

- Bastien, Sheila PhD. 1992, *Patterns of Neuropsychological Abnormalities and Cognitive Impairment in Adults and Children* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa

- Cheney, Paul M.D. 2006, *The Heart of the Matter* [video recording], Available: <http://www.hfme.org/wcheney.htm>
- Dowsett, Elizabeth MBChB. 2001, *THE LATE EFFECTS OF ME Can they be distinguished from the Post-polio syndrome?* [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. 2000, *Mobility problems in ME* [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. 1999a, *Redefinitions of ME* [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. 1999b, *Research into ME 1988 - 1998 Too much PHILOSOPHY and too little BASIC SCIENCE!*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. n.d.a, *Differences between ME and CFS*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. n.d.b, *Time to put the exercise cure to rest*, [Online], Available: <http://www.hfme.org/wdowsett.htm>
- Dowsett, Elizabeth MBChB. in: Colby, Jane 1996, *ME: The New Plague*, Ipswitch Book Company, Ipswitch.
- Dowsett E. & Ramsay, A.M. n.d., '*Myalgic Encephalomyelitis: Then and Now*' *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, B. Hyde (ed.), The Nightingale Foundation, Ottawa, pp. 81-84.
- Dowsett E., Ramsay A.M., McCartney A.R., & Bell E.J. 1990, '*Myalgic Encephalomyelitis: A persistent Enteroviral Infection?*' in *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, B. Hyde (ed.), The Nightingale Foundation, Ottawa, pp. 285-291.
- Hooper, M 2006, Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research J. Clin. Pathol. published online 25 Aug 2006; doi:10.1136/jcp.2006.042408 Available: <http://jcp.bmjournals.com/cgi/content/abstract/jcp.2006.042408v1> and [http://www.hfme.org/Other/ME\\_A\\_Review\\_by\\_Hooper.pdf](http://www.hfme.org/Other/ME_A_Review_by_Hooper.pdf)
- Hooper, M. & Marshall E.P. 2005, *Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis* [Online], Available: <http://www.hfme.org/whooper.htm> [Note: This paper is 174 pages]
- Hooper, M. 2003, *The MENTAL HEALTH MOVEMENT: PERSECUTION OF PATIENTS?* [Online], Available: <http://www.hfme.org/whooper.htm>
- Hooper, M. Marshall E.P. & Williams, M. 2001, *What is ME? What is CFS? Information for Clinicians and Lawyers*, [Online], Available: <http://www.hfme.org/whooper.htm>
- Hyde, Byron M.D. 2006, *A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis & An Irreverent History of Chronic Fatigue Syndrome* [Online], Available: <http://www.hfme.org/whyde.htm>
- Hyde, Byron M.D. 2007, *The Nightingale Definition of Myalgic Encephalomyelitis* [Online], Available: [www.hfme.org/whyde.htm](http://www.hfme.org/whyde.htm)

- Hyde, Byron M.D. 2003, *The Complexities of Diagnosis* in (ed) Jason, Leonard at et al. 2003 *Handbook of Chronic Fatigue Syndrome* by Ross Wiley and Sons, USA. Available: <http://www.hfme.org/whyde.htm>
- Hyde, Byron M.D. 1992, *Preface* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa.
- Hyde, Byron M.D. & Anil Jain M.D. 1992, *Clinical Observations of Central Nervous System Dysfunction in Post Infectious, Acute Onset M.E.* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa, pp. 38-65.
- Hyde, Byron M.D., Bastien S Ph.D. & Anil Jain M.D. 1992, *General Information, Post Infectious, Acute Onset M.E.* in Hyde, Byron M.D. (ed) 1992, *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Nightingale Research Foundation, Ottawa, pp. 25-37.
- Ramsay, A. 1988, *Myalgic Encephalomyelitis and Postviral Fatigue States: The saga of Royal Free Disease*, Gower Medical Publishing, London.
- Ramsay, Melvin Dr. ME Association Newsletter, Winter 1989: pp. 20-21.
- Ramsay, Melvin A. 1986 *MYALGIC ENCEPHALOMYELITIS : A Baffling Syndrome With a Tragic Aftermath*. [Online], Available: <http://www.hfme.org/wramsay.htm>
- Richardson, J. n.d., 'M.E., *The Epidemiological and Clinical Observations of a Rural Practitioner,*' *The Clinical and Scientific Basis of Myalgic Encephalomyelitis*, Hyde, Byron M.D. (ed) The Nightingale Foundation, Ottawa, pp. 85-94.
- Verillo, Erica F & Gellman, Lauren M 1997, *CFIDS - A Treatment Guide*, St. Martin's Griffin, New York

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

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

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

In future, it is essential that M.E. research again be conducted using only M.E.

defined patients and using only the term M.E. The bogus, financially-motivated disease category of ‘CFS’ must be abandoned.

2. The research referred to on this website varies considerably in quality. Some is of a high scientific standard and relates wholly to M.E. and uses the correct terminology. Other studies are included which may only have partial or minor possible relevance to M.E., use unscientific terms/concepts such as ‘CFS,’ ‘ME/CFS,’ ‘CFS/ME,’ ‘CFIDS’ or Myalgic ‘Encephalopathy’ and also include a significant amount of misinformation. Before reading this research it is also essential that the reader be aware of the most commonly used ‘CFS’ propaganda, as explained in [A warning on ‘CFS’ and ‘ME/CFS’ research and advocacy](#) and in more detail in [Putting Research and Articles on M.E. into Context](#).

**Disclaimer:** The descriptions of symptoms in this paper are not intended to form a definitive definition of M.E. This paper is not intended for use as a diagnostic tool. The HFME does not dispense medical advice or recommend treatment, and assumes no responsibility for treatments undertaken by visitors to the site. It is a resource providing information for education, research and advocacy only. Please consult your own health-care provider regarding any medical issues relating to the diagnosis or treatment of any medical condition.

**Permission is given for this document to be freely redistributed** by e-mail or in print for any not-for-profit purpose provided that the entire text (including this notice and the author’s attribution) is reproduced in full and without alteration. Please redistribute this text widely.

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

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

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

COPYRIGHT © JODI BASSETT JANUARY 2009. UPDATED JUNE 2012. FROM  
WWW.HFME.ORG



- Myalgic Encephalomyelitis (M.E.) is a disabling neurological disease that is very similar to Multiple Sclerosis (M.S.) and Poliomyelitis. Earlier names for M.E. were 'atypical Multiple Sclerosis' and 'atypical Polio.'
- M.E. is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This damage is an essential part of 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, tis = 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. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.
- M.E. 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.
- M.E. 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.
- M.E. can be more disabling than M.S. or Polio, and many other serious diseases. M.E. is one of the most disabling diseases that exists. 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 M.E. 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 and 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 (e.g. 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.*

- M.E. 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 (e.g. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E. M.E. is a long-term/lifelong neurological disease that affects hundreds of thousands of adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)



This paper is included in the new *Caring for the M.E. Patient* book by Jodi Bassett.

The book also includes a Foreword by the world's most experienced M.E. expert Dr Byron Hyde and is essential reading for anyone with an interest in M.E.

For more information on all digital and printed HFME books please visit the *HFME Books* page on [www.hfme.org](http://www.hfme.org)