

# Clinical Observations of Myalgic Encephalomyelitis

## 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; 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 & Co-Morbid Entities.

## **CARDIAC & CARDIOVASCULAR DYSFUNCTIONS**

- Reduced maximum heart rate and/or an elevated resting heart rate
- Extreme pallor (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)
- 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.
- Sensations of chest pain, chest pressure or fluttering sensations in the mid-chest, palpitations (skipped heart beats), tachycardia (rapid heart beat – may be 170bpm 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.)

- 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 recognize faces, even those of close friends and family)

## **COGNITIVE & NEUROLOGICAL DYSFUNCTIONS (Continued)**

- **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 eg. 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 a short period of time may become extremely difficult, or impossible. 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, 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 & apparent non sequiturs. Patients 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. Word retrieval is difficult. 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).**

## **COGNITIVE & NEUROLOGICAL DYSFUNCTIONS (Continued)**

- **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 people 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.**
- **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 - recognizing colours but forgetting what they mean, (Seeing the red light at an intersection, knowing it is red, but not recognizing that red means 'stop,' for example)**
- **Abstract reasoning dysfunction; difficulty organizing, 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**

## **COGNITIVE & NEUROLOGICAL DYSFUNCTIONS (Continued)**

- 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 (ranging from mild to a total intolerance)

## **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.
- 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.
- Loss of the natural antidepressant effect of exercise
- Inappropriate signs of immune system activation can be brought on by overexertion

## **HEADACHES**

- Onset of a new type, severity or pattern of headaches is common. Dr Hyde (Cdn ME Expert) explains M.E. can cause a unique type of 'severe headaches of a type never previously experienced.' This is often associated with neck rigidity, occipital pain (pain/pressure felt at the base of the skull, the top of the neck) and/or retro-orbital eye pain (behind the eyes) & also sometimes pain behind 1 or both ears. 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 .
- Tinnitus - ringing, buzzing, humming, clicking, popping & 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) or a sensitivity to motion/movement (which can affect balance)
- Nystagmus - a rapid involuntary oscillation of the eyeballs
- The voice may become weak, hoarse or fall to a whisper, 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.

## **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 often and low body temperature)
- Very severe throat pain, scratchiness & tenderness which often worsens with exercise, exertion or before relapses. Throat may also feel clogged & require constant clearing. Throat may appear red or have characteristic 'crimson crescents' around the tonsillar membranes of upper throat
- An increased susceptibility to secondary infections can be a significant problem. In addition to seasonal colds & flu patients are also more susceptible to upper respiratory tract or urinary tract infections, topical fungal infections & recurring shingles. All of these infections also last longer, can be more severe & occur more frequently & may also cause relapses either concurrently or just after the initial infection. Even in cases where prior immunity has been established.
- \*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.

## **IMMUNE SYSTEM DYSFUNCTIONS continued**

- 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.
- 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.
- Transient tingling, numbness and/or burning sensations (or other odd sensations) in the face or extremities (paresthesias).
- 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
- 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

## **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 (on waking or with exertion), which can be severe.
- Persistent coughing and wheezing

## **PAIN**

Three different types of muscle pain in M.E.:

- 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.
- 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.
- Occurs after a particular muscle group has been in use for an extended period; the affected muscles become weak/paralyzed 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 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)

## **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/dysphagia (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.
- Myoclonus (strong involuntary jerks of the arms, legs or entire body)

## **SKIN, HAIR & NAILS**

- Skin: extreme pallor, rashes, dry and peeling skin, acne, spontaneous bruising, fungal infections, butterfly rash on face, flushing of face, fingerpads may be atrophic so that the fingerprints are hard to see, skin may become red and shiny (generally after long-term illness). This is sometimes referred to as a 'destruction of fingerprints.'
- Hair: hair loss and poor quality regrowth.

## **SLEEP DYSFUNCTIONS**

- Unrefreshing sleep (waking up feeling worse than when you went to bed)
- 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.

## **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:**

- Increased tendency for Mitral Valve Prolapse, especially in children (breathlessness, fatigue)
- 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
- Raynauds phenomenon (poor circulation)
- 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)

## **CO-MORBID ENTITIES:**

- 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)



This list was compiled by Wendy Boutilier who has moderate to severe Myalgic Encephalomyelitis since 2009 following 2 bouts of Dengue Fever (DENV1,2,3,4) and Strep Throat that morphed into Necrotising Fasciitis with full Sepsis. Diagnosed by use of SPECT Scans, 2 Day Nuclear CPET and patient experience by a Professor at the University of West Indies & Expert at Tropical Diseases using Ramsay Criteria and reconfirmed in 2012 by Canadian Doctor as per the ICC 2011. Any errors are mine.

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 sources for this list are:**

- The book 'The Clinical and Scientific Basis of Myalgic Encephalomyelitis' edited by Dr Byron Hyde
- Papers on Myalgic Encephalomyelitis by Dr Byron Hyde
- Papers on Myalgic Encephalomyelitis by Dr Melvin Ramsay
- Papers on Myalgic Encephalomyelitis by Dr Elizabeth Dowsett
- Papers/lectures by Dr Paul Cheney
- Dr Bruce Carruthers et al for the ICC 2011 ME criteria