

## **The misdiagnosis of 'CFS'**

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The fact that a person qualifies for a diagnosis of Oxford Chronic Fatigue Syndrome (CFS), Fukuda (CDC) CFS, or either of the Australian CFS definitions (a) does not mean that the patient has Myalgic Encephalomyelitis (M.E.), and (b) does not mean that the patient has any other distinct and specific illness named 'CFS.' **A diagnosis of 'CFS' – based on these or any of the other 'CFS' definitions – can only ever be a *misdiagnosis*.**

The reason for this is that despite the fact that the new name and definition of 'CFS' were created in a response to an outbreak of what was unmistakably M.E., this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process which did not, and could not exist. (Hooper et al. 2001, [Online]) (Dowsett n.d.a. [Online]) (Hyde 2006, [Online]) As M.E. expert Dr Byron Hyde explains:

Do not for one minute believe that CFS is simply another name for Myalgic Encephalomyelitis. It is not. The CDC 1988 definition of CFS describes a non-existing chimera based upon inexperienced individuals who lack any historical knowledge of this disease process. The CDC definition is not a disease process. It is (a) a partial mix of infectious mononucleosis /glandular fever, (b) a mix of some of the least important aspects of M.E. and (c) what amounts to a possibly unintended psychiatric slant to an epidemic and endemic disease process of major importance. Any disease process that has major criteria, of excluding all other disease processes, is simply not a disease at all; it doesn't exist. The CFS definitions were written in such a manner that CFS becomes like a desert mirage: The closer you approach, the faster it disappears and the more problematic it becomes (2006, [Online]).

As Professor Malcolm Hooper explains, 'As a basis for sound scientific research, [CFS] has been a disaster.' (2001, [Online]) Today there are more than nine different 'CFS' definitions. Just like the original definition of 'CFS' produced in 1988 however, none of these definitions defines any distinct illness, including Myalgic Encephalomyelitis. (Hyde 2006, [Online]) All each of these flawed 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.

(Hooper et al 2001, [Online]) (Dowsett 2001b, [Online]) This is why being diagnosed with any of the definitions of ‘CFS’ is not a useful or meaningful diagnosis and why a diagnosis of ‘CFS’ should never be accepted – by doctor or by patient – as an end point of the process of diagnosis.

The creation of the flawed disease category of ‘CFS’ (and the equally flawed government policies that have gone along with it) have had a devastating effect on hundreds of thousands of M.E. sufferers around the world, including young children. These very ill patients are often denied appropriate medical treatment and care, denied appropriate insurance entitlements and other medical benefits and are often accused of malingering by doctors, welfare agencies and the media (and in turn even their own friends and family). M.E. patients are also routinely recommended or forced to participate in inappropriate or harmful psychologically based interventions while basic appropriate medical care is withheld. These harmful interventions (and the lack of basic medical care) have had disastrous and long-term physical effects on many sufferers. In some cases this has resulted in death. (Hooper et al. 2001, [Online]) (Hyde 2003, [Online])

Patients with M.E. are not the only patient group to be negatively affected however. Other patient groups misdiagnosed with ‘CFS’ are also denied appropriate diagnosis and treatment. They may also be subjected to inappropriate psychological interventions. Doctors, researchers and the general public are also negatively affected in various ways by this subterfuge (As explained previously in Smoke and Mirrors). The only groups which gain from the ‘CFS’ confusion are insurance companies and various other organisations and corporations which have a vested financial interest in how these patients are treated, including the government.

**The only way forward for every group involved is that the disease category of ‘CFS’ must be abandoned.** (Hooper 2006, [Online]) Each of the patient groups involved must be correctly diagnosed and then treated as appropriate based on legitimate and unbiased science involving the SAME patient group. People with M.E. must be diagnosed and treated for M.E. Patients with depression should be diagnosed and treated for depression. Patients with cancer should be treated for cancer, and so on. Lumping these disparate patient groups together under a vague and meaningless category of ‘fatiguing illnesses’ only hinders each of the patient groups involved in their battle to regain their health. (Dowsett 2001b, [Online]) (Hooper 2006, [Online]) (Hyde 2003, [Online])

What a diagnosis of ‘CFS’ actually means is that the patient has a gradual onset fatigue syndrome which is usually due to a *missed major disease*. i.e. the patient has:

a. Missed cardiac disease, b. Missed malignancy, c. Missed vascular disease, d. Missed brain lesion either of a vascular or space occupying lesion, e. Missed test positive rheumatologic disease, f. Missed test negative rheumatologic disease, g. Missed endocrine disease, h. Missed physiological disease, i. Missed genetic disease, j. Missed chronic infectious disease, k. Missed pharmacological or immunization induced disease, l. Missed social disease, m. Missed drug use disease or habituation, n. Missed dietary dysfunction diseases, o. Missed psychiatric disease. (Hyde 2006, [Online])

Some of the illnesses commonly misdiagnosed as ‘CFS’ include:

- Various post-viral fatigue states/post-viral fatigue syndromes (eg. following glandular fever/mononucleosis, hepatitis, Ross river virus, Q fever, flu, measles, chickenpox, herpes and many other infections)
- Fibromyalgia
- Candida
- Athlete over-training syndrome
- ‘Burnout’
- Multiple chemical sensitivity syndrome (MCSS)
- Multiple sclerosis
- Thyroid illness
- Adrenal insufficiency
- Localised and Metastatic malignancies
- Brain tumours, including astrocytomas, gliomas
- Transverse Myelitis
- Post-polio syndrome
- Myopathic illnesses including: Myasthenia gravis, Mitochondrial myopathies, Post-infectious polymyositis
- Vitamin B12 deficiency disorders: Pernicious anaemia, Intentional dietary deprivation, Intestinal disease associated with or independent of M.E.
- Rheumatoid illness or lupus (SLE)
- Sarcoma
- Renal or liver disease
- Infectious illnesses including: Toxoplasmosis, AIDS, Lyme disease (*Borrelia burgdorferi*), Tuberculosis, Brucellosis
- Various psychiatric and social psychiatric states including: Anxiety neurosis, Uncomplicated endogenous or reactive depression, Clinical depression, Psychopathic personality disorder, Post-traumatic stress disorder (PTSD), Schizophrenia and other psychiatric disease (Ramsay 1986, [Online]) (Ramsay 1988) (Hyde 1992, p 22) (Dowsett n.d.a. [Online]) (Hooper et al. 2001, [Online]) (Hyde 2003, [Online]) (Hyde 2006, [Online])

This is of course not a comprehensive list. M.E. expert Dr Elizabeth Dowsett explains that, ‘There are actually 30 well documented causes of ‘chronic fatigue.’’ (n.d.a. [Online]) It should also be remembered that although none of the ‘CFS’ definitions define M.E., the majority of those with M.E. will be given a ‘CFS’ diagnosis by default (due to the ignorance surrounding M.E., and the confusion with ‘CFS’). Therefore although most of those given a misdiagnosis of ‘CFS’ will not have M.E., the possibility that a patient misdiagnosed with ‘CFS’ has authentic Myalgic Encephalomyelitis should also be investigated, along with these myriad other possibilities.

Today patients with all sorts of different illnesses are commonly misdiagnosed as having ‘CFS.’ Under cover of the bogus disease category of ‘CFS’ this diverse mix of patients are treated as if they each suffered the exact same specific illness. This is clearly unscientific, and unethical. These patients must be given the opportunity to be diagnosed correctly if they are to have any chance of appropriate treatment or recovery, not given a meaningless ‘CFS’ misdiagnosis. Patients with M.E. need this same opportunity. Treating this diverse and heterogeneous patient group as if their illnesses each shared the same symptoms, aetiology, pathology and response to treatment is inappropriate and highly unlikely to benefit the health and wellbeing of any of the patient groups involved. Treating this ‘CFS’ group as if they each shared a specific psychological or behavioural illness is also clearly inappropriate. Aside from representing a heterogeneous patient group, many (likely the vast majority) of those with the diagnosis are not mentally ill, and do not suffer from behavioural problems. (This includes of course, those patients with authentic M.E.) (Hooper 2006, [Online]) (Hyde 2006, [Online]) (Hooper et al. 2001, [Online])

For the benefit of all of the patient groups involved, doctors must return to the age-old medical principals of correct diagnosis (a) careful history, (b) detailed physical examination and (c) appropriate investigation. (Hyde 2006, [Online]) As Dr Byron Hyde explains:

Although the authors of these definitions have repeatedly stated that they are defining a syndrome and not a specific disease, patient, physician, and insurer alike have tended to treat this syndrome as a specific disease or illness, with at times a potentially specific treatment and a specific outcome. This has resulted in much confusion. (2006, [Online]) Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would have told the students to search for an occult malignancy, cardiac or other organ disease, or chronic infection. The concept that there is an entity called chronic fatigue syndrome has totally altered that essential medical guideline. Patients are now being diagnosed with CFS as

though it were a disease. It is not. It is a patchwork of symptoms that could mean anything. (2003, [Online])

Physicians who diagnose ‘CFS’ in any patient experiencing new onset fatigue without looking and testing for the true cause of the symptoms do their patients – and themselves – a great disservice. As Dr Elizabeth Dowsett explains, ‘There is no such disease(s) as CFS’ (n.d.a. [Online]) Some of the conditions commonly misdiagnosed as CFS are very well defined and well-known illnesses and very treatable – but only once they have been correctly diagnosed. Some conditions are also very serious or can even be fatal if not correctly diagnosed and managed, including Myalgic Encephalomyelitis.

Every patient deserves the best possible opportunity for appropriate treatment for their illness, and for recovery. This process must begin with a correct diagnosis if at all possible. **A correct diagnosis is half the battle won.**

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### **For more information:**

- PART 2 of this paper lists the symptoms of some of the illnesses commonly misdiagnosed as CFS, and compares them with the CFS definitions. If you have been misdiagnosed with 'CFS' and aren't sure what to do next, see the new must-read paper: Where to after a 'CFS' (mis)diagnosis? and Additional question and answer session on the text.
- M.E. is a distinct, recognisable entity; an acute onset organic neurological disease that can be diagnosed relatively early in the course of the disease, providing the physician has some experience with the illness. The Nightingale Definition of M.E. – a testable definition of M.E. finally – now also makes diagnosis easier than ever before even for those with no experience with the illness. For information on how authentic M.E. is characterised and diagnosed see: Testing for Myalgic Encephalomyelitis and What is Myalgic Encephalomyelitis? The excellent papers by Dr Byron Hyde, a doctor with over 20 years experience with M.E. (and who is also very knowledgeable about ‘CFS’ and has seen a vast number of patients misdiagnosed with ‘CFS’) and regarded by many as today’s leading M.E. expert are also essential extra reading, see: A New and Simple Definition of Myalgic Encephalomyelitis and a New Simple Definition of Chronic Fatigue Syndrome and The Complexities of Diagnosis and his newest paper: The Nightingale Definition of M.E.
- For more information on the harm caused by the psychological approach to M.E. due to the confusion between M.E. and ‘CFS’ by interventions such as CBT and GET see: Smoke and Mirrors, The effects of CBT and GET on

patients with Myalgic Encephalomyelitis and Section 5: and Section 6: of the CBT and GET online database.

- 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 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.
  2. **Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely 'fatigued' instead of having M.E. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

M.E. is not synonymous with 'CFS' and nor is it a subgroup of 'CFS.' (There is no such thing as a subgroup of CFS; there is no such disease/s as 'CFS.')

M.E. is not a primarily fatiguing condition, nor is it a wastebasket diagnosis or 'medically unexplained' as 'CFS' is. Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming

‘CFS’ with some variation on the term M.E. would achieve nothing and only create yet more confusion and mistreatment. The problem is not that ‘CFS’ patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually *do* have psychological illnesses. *There is no such distinct disease as ‘CFS’* – that is the entire issue, and the vast majority of patients misdiagnosed with CFS *do not* have M.E. and so for them that term is as incorrect as ‘cancer’ or ‘diabetes.’

For more information on why the bogus disease category of 'CFS' must be abandoned, (along with the use of other vague and misleading umbrella terms such as ‘ME/CFS’ ‘CFS/ME’ 'CFIDS' and 'Myalgic Encephalopathy' and others), see: [Who benefits from 'CFS' and 'ME/CFS'?](#), [Problems with the so-called "Fair name" campaign: Why it is in the best interests of all patient groups involved to reject and strongly oppose this misleading and counter-productive proposal to rename ‘CFS’ as ‘ME/CFS’](#) and [Problems with the use of 'ME/CFS' by M.E. advocates, plus The misdiagnosis of CFS, Why the disease category of ‘CFS’ must be abandoned and Smoke and Mirrors](#)

### **References (and recommended additional reading list)**

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. *These doctors have also dealt with a vast number of patients misdiagnosed as ‘CFS.’* Again, more experienced, more knowledgeable and more credible M.E. (and ‘CFS’) 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., and the difference between M.E. and ‘CFS.’ 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 this topic. For more information see the [References](#) page.

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

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

**The misdiagnosis of 'CFS' – Part 2**

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A symptom comparison between several definitions of 'CFS' and some of the illnesses most commonly misdiagnosed as 'CFS.'

**The most commonly used definitions of CFS are:**

- **The US 1994 Fukuda (or CDC) definition of CFS.** This definition was created by Keiji Fukuda, Stephen Straus, Ian Hickie, Michael Sharpe, James Dobbins and Anthony Komaroff in the US in 1992, and was revised in 1994. This definition requires that a patient experience new onset of **fatigue**, plus four or more of the following symptoms; **impaired memory or concentration, sore throat, tender cervical or axillary lymph nodes, muscle pain, multi-joint pain, new headaches, unrefreshing sleep or post-exertional malaise**. Psychiatric illness is not an exclusion criteria (only major psychiatric illness such as psychotic depression, bipolar disorder and schizophrenia are excluded). It should also be noted that in many recent studies (including the latest CDC CFS research) a modified version of this criteria is being used whereby the condition that a patient have four of the eight symptoms listed is waived and a patient is said to qualify for the diagnosis **purely on the presence of the symptom of fatigue**.
- **The UK 1991 Oxford definition of CFS.** This definition was created by Michael C. Sharpe, Len Archard, Jangu Banatvala, Simon Wessely, A. David, Peter White *et al.* in the UK. **Fatigue** is the only symptom which is essential for the diagnosis of Oxford CFS. The symptom of fatigue was defined by this group as being not organic in origin and as a psychiatric condition - a form of avoidance or symptom of depression. Psychiatric illness is not an exclusion criterion for Oxford CFS.
- **Australian definitions of CFS - 1988 and 1990.** Andrew Lloyd, Denis Wakefield, Clement R. Boughton and John Dwyer in 1988. Andrew Lloyd, Ian Hickie, Clement R. Boughton, Owen Spencer and Denis Wakefield in 1990. The 1988 Australian CFS definition was a definition of post-viral fatigue syndrome or fatigue state caused by viral illnesses including glandular fever, and Q fever. It is described as a state of **prolonged fatigue following a viral illness**. By definition the condition is self-limiting and the physical effects will be resolved in two years or less. In 1990 the definition of post-viral fatigue was more closely aligned with the psychiatric model of

fatigue. To fit this second definition patients must have: 1. **Fatigue** 2. **Impairment of concentration and new onset of short-term memory impairment**, and 3. No alternative diagnosis found by history or physical exam over a six-month period. Psychiatric illness is not an exclusion criteria.

None of these CFS definitions is a description of any neurological disease, including Myalgic Encephalomyelitis. M.E. is not defined by 'fatigue' is not 'medically unexplained' and is certainly not merely a diagnosis of exclusion. M.E. is a distinct organic neurological disease. The summaries of each of these CFS definitions were taken from the paper ME and CFS, the Definitions produced by the Committee for Justice and Recognition of M.E. For more information on the definitions of M.E. and CFS see this paper, and: The Definitions of M.E. (and CFS) and The Nightingale Definition of M.E.

### **Symptom comparison lists of some of the illnesses most commonly misdiagnosed as CFS:**

**Post viral fatigue states and fatigue syndromes** (eg. following glandular fever/mononucleosis, hepatitis, Ross river virus, flu, Q fever and many other infections)

Symptoms of post-glandular fever/mononucleosis fatigue syndrome include: severe fatigue not satisfied by sleep, recurrent tonsillitis, chronic sore throat and swollen lymph glands in the neck, aches and pains in the limbs, brain 'fog,' lack of concentration, depression, deep lethargy, not being able to stand lots of noise, people or strong smells (perfume, cleaning materials etc.), pins and needles, not feeling all there, feelings of having no energy, and various glandular fever/mononucleosis symptoms. (Reference)

### **Fibromyalgia**

The two primary criteria for the classification of Fibromyalgia are: 1) A history of widespread pain involving all four quadrants of the body (right side, left side, above waist, below waist) for a period of at least 3 months. 2) Upon physical examination, the presence of pain in at least 11 of 18 tender points when touched or pressed with force amounting to the equivalent of 4 kg or 9 lbs, although some physicians will diagnose Fibromyalgia without these. (Reference) Other symptoms may include: Tenderness in the neck, shoulder, knee, elbow, or upper buttocks or thigh areas. Trouble sleeping. Tiredness in the morning or late in the day. Mood changes. Headaches. Difficulty concentrating. Numbness and tingling in hands, arms, feet, legs or face. Abdominal pain. Bloating. Constipation. Diarrhea. (Reference)

### **Candida**

Symptoms of systemic fungal infection (candida) include: Allergies to foods and/or airborne chemicals, continual fatigue often more noticeable after eating,

poor digestion, constipation, diarrhoea, gas, bloating, cramps, heartburn, sugar craving, irritability, mood swings, headaches, migraine, a 'fogged in' feeling, poor concentration, dizziness, depression, anxiety, vaginal infections, menstrual problems, impotence, infertility, prostatitis, rectal itch, urinary infections, catches colds and flu easily, congestion, post nasal drip, asthma, bronchitis, earaches, sore throats, athlete's foot, jock itch, hives, psoriasis, skin rashes, hyperactivity, feeling bad all over, cold extremities, aches, white coated tongue upon rising. ([Reference](#))

### **Athletes over training syndrome**

Symptoms of athletes over-training syndrome include: a washed-out feeling, tiredness, feeling drained, lack of energy, mild leg soreness, general achiness, pain in muscles and joints, sudden drop in performance, insomnia, headaches, increased number of colds, sore throats, decrease in training capacity or intensity, moodiness, irritability, depression, loss of enthusiasm for the sport, decreased appetite, increased incidence of injuries. ([Reference](#))

### **Burnout**

The symptoms of burnout can include: physical fatigue, frequent illness, sleep problems, disillusionment, the loss of a sense of meaning and cynicism towards others, feelings of helplessness, frustration of efforts and a lack of power to change events, strong feelings of anger against the people we hold responsible for the situation, feelings of depression and isolation, increasing detachment from co-workers, marked reduction in commitment to work, increased alcohol consumption. ([Reference](#))

### **MCS or MCSS**

People with MCS have reported a wide range of symptoms including: headache, fatigue, dizziness, nausea, irritability, confusion, difficulty concentrating, intolerance to heat or cold, earache, stuffy head or congestion, itching, sneezing, sore throat, memory problems, breathing problems, changes in heart rhythm, chest pain, muscle pain and/or stiffness, bloating or gas, diarrhea, skin rash or hives, mood changes. ([Reference](#))

### **Multiple sclerosis**

Symptoms of M.S. can include: severe fatigue or lassitude, numbness (and/or tingling) of the face, body, or extremities (arms and legs), feeling of detachment in the body, freezing cold hands and feet, (actual or sensations of), impaired sensations of heat, cold, sudden energy loss that leaves the person dazed and unable to communicate; may fall asleep suddenly, vertigo that may be so severe it can be accompanied by vomiting and nausea and an inability to walk in a straight line, sudden need to urinate, incontinence, urinary retention, pain that varies in type and severity (includes aching joints, burning, shooting, stabbing,

cramping, facial nerve pain), weakness in the body (arms, legs feel like lead, sensation of having to drag legs along), lack of co-ordination, lack of balance, walking in a drunken stagger, weakness and paralysis, muscle stiffness, clumsiness, minor and temporary flaring in symptoms (pain, loss of energy) after exercise, tinnitus, hearing impairment (words sound scrambled and non-sensical), blurred double vision, blind spots, colour dimming, partial loss of sight, speech difficulties, slurring, jerky speech, garbled speech, impotence, loss of sexual sensation, emotional lability, short-term memory loss, e.g. going to the wrong place, problems concentrating and reasoning, food allergies, dietary sensitivities. ([Reference](#))

### **Post polio syndrome**

PPS can strike polio survivors anywhere from 10 to 40 years after their recovery (complete or partial) from polio and is estimated to affect 40 – 80% of this patient group. Symptoms may occur after surgery or an illness or severe repeated overexertion and include a gradual onset of fatigue, progressive muscle weakness, muscle pain, joint pain, breathing and swallowing difficulties. Muscle and joint pain, breathing or swallowing problems, decreased tolerance of cold temperatures and muscular atrophy. Energy conservation and pacing are an important part of treatment. Blood tests are usually normal. Post polio syndrome is a very slowly progressing condition marked by long periods of stability. ([Reference](#)) ([Reference](#)) ([Reference](#)).

### **Dysautonomia**

Dysautonomia is a broad term that describes any disease or malfunction of the autonomic nervous system. This includes postural orthostatic tachycardia syndrome (POTS), vasovagal syncope, mitral valve prolapse dysautonomia, pure autonomic failure, Neuro Cardiogenic Syncope (NCS), Neurally Mediated Hypotension (NMH) autonomic instability and a number of lesser-known disorders. Symptoms can include excessive fatigue, excessive thirst, lightheadedness, dizziness or vertigo, feelings of anxiety or panic (not mentally induced), rapid heart rate or slow heart rate, orthostatic hypotension plus headaches, pallor, malaise, facial flushing, constipation, diarrhea, nausea, acid reflux, visual disturbances, orthostatic hypotension, numbness, nerve pain, trouble breathing, chest pains, in some cases loss of consciousness and seizures. ([Reference](#))

### **Acute Disseminated Encephalomyelitis (ADEM)**

Acute disseminated encephalomyelitis (ADEM) is classically described as a uniphasic syndrome occurring in association with an immunization or vaccination (postvaccination encephalomyelitis) or systemic viral infection (parainfectious encephalomyelitis). Acute disseminated encephalomyelitis (ADEM) is an uncommon monophasic inflammatory demyelinating disease that

usually presents in children and young adults. The majority of children make a full recovery. ADEM should be suspected in a child with fever, fatigue and neurologic abnormalities, including impaired consciousness, especially one to two weeks after a viral infection. ([Reference](#)) ([Reference](#))

### **Chiari Malformation**

Headache, dizziness, difficulty sleeping, weakness in arms/hands, neck pain, numbness/tingling in arm/hand, fatigue, nausea, shortness of breath, blurred Vision, tinnitus, difficulty swallowing, and leg weakness. Plus, depression, body weakness, balance problems, memory problems, leg/foot numbness, hoarse voice, chest pain, facial numbness, anxiety, slurred speech, arm pain, abdominal pain, photophobia. Less commonly also: tachycardia, trouble hearing, vomiting, double vision, word-finding problems, vision loss, blackouts, apnea, vertigo, loss of peripheral vision, nystagmus, earache, nosebleeds, snoring, thoracic pain, hypotension, waking up choking, leg pain, palpitations, hypertension, abnormal gag reflex, face pain/tingling. (Diagnosis is by MRI brain scan.) Source: Mueller DM, Oro' JJ Prospective analysis of presenting symptoms among 265 patients with radiographic evidence of Chiari Malformation type 1 with or without Syringomyelia.

### **Devic's disease, Devic's syndrome or neuromyelitis optica (NMO)**

The main symptoms of Devic's disease are loss of vision and spinal cord function. As for other etiologies of optic neuritis, the visual impairment usually manifests as decreased visual acuity, although visual field defects, or loss of color vision may occur in isolation or prior to formal loss of acuity. Spinal cord dysfunction can lead to muscle weakness, reduced sensation, or loss of bladder and bowel control. The typical patient has an acute and severe spastic weakness of the legs (paraparesis) or all four limbs (tetraparesis) with sensory signs, often accompanied by loss of bladder control. ([Reference](#))

### **Thyroid illness**

Signs and symptoms of Hypothyroidism include: weak slow heart beat, muscular weakness and constant fatigue, sensitivity to cold, thick puffy skin, slowed mental processes and poor memory, constipation, goitre. Signs and symptoms of Hyperthyroidism include: rapid forceful heartbeat, tremor, muscular weakness, weight loss in spite of increased appetite, restlessness, anxiety and sleeplessness, profuse sweating and heat intolerance, diarrhea, eye changes, goitre. ([Reference](#))

### **Adrenal insufficiency**

Symptoms of adrenal insufficiency include: fatigue and loss of energy, loss of appetite, nausea, vomiting, diarrhea, abdominal pain, weight loss, muscle weakness, dizziness when standing, dehydration, anxiety and depression,

increased bronze pigmentation of the skin and mucous membranes and decreased tolerance to cold. Women lose pubic and underarm hair and stop having normal menstrual periods. ([Reference](#))

### **Localised and Metastatic malignancies (cancer)**

Early symptoms of cancer can include: chronic fatigue, weakness, dizziness, drowsiness, a change in bowel or bladder habits, loss of feeling in arms or legs or difficulties in walking, a persistent cough or coughing blood, constant indigestion or trouble swallowing; unusual bleeding, paleness; fever and flu-like symptoms, bruising and prolonged bleeding, enlarged lymph nodes, digestive discomfort, discomfort or pain in the abdomen; nausea and vomiting, diarrhea or constipation, bloating after meals, headaches that tend to be worse in the morning and ease during the day, that may be accompanied by nausea or vomiting, pain in bones and joints, frequent infections, changes in personality, memory or speech, weight loss; night sweats (Note that symptoms vary depending on the type of cancer) ([Reference](#))

### **Brain tumours, including astrocytomas, gliomas**

Symptoms of brain tumour can include: fatigue, sluggishness and drowsiness, headache (usually just after waking and lessening as the day goes on), vomiting, uncoordinated clumsy movements, seizures. muscle weakness on one side of the face causing a one-sided smile or drooping eyelid, difficulty with swallowing and with speech, personality changes, weakness, muscle wasting or spasms, and sensory changes ([Reference](#))

### **Transverse Myelitis**

Symptoms of Transverse Myelitis include: limb weakness, sensory disturbance, bowel and bladder dysfunction, back pain and radicular pain (pain in the distribution of a single spinal nerve), sensation is diminished below the level of spinal cord involvement, tingling or numbness in the legs, pain, temperature sensation is diminished, appreciation of vibration (as caused by a tuning fork) and joint position sense may also be decreased, bladder and bowel sphincter control are disturbed in the majority of patients. Many patients with TM report a tight banding or girdle-like sensation around the trunk and that area may be very sensitive to touch. ([Reference](#))

### **Myasthenia gravis**

The symptoms of myasthenia gravis can include: severe and generalised muscle weakness (the first noticeable symptom frequently is weakness of the eye muscles). The disease may remain localised there, or progress to muscles involved in swallowing, chewing, talking, or in moving the limbs. Symptoms vary from patient, but can include a drooping of one or both the eyelids (ptosis), blurred or double vision, weakness of the muscles that move the eyeballs, and

unstable or waddling gait, weakness in arms, hands, and fingers, difficulty in swallowing, and difficulty in breathing. Weakness tends to worsen with exercise and at the end of the day, and is usually particularly alleviated by rest. ([Reference](#))

### **Mitochondrial myopathies**

Depending on which cells of the body are affected, symptoms of mitochondrial myopathies can include: Poor growth, loss of muscle coordination, muscle weakness, visual and/or hearing problems, developmental delays, learning disabilities, mental retardation, heart, liver, or kidney disease, gastrointestinal disorders, severe constipation, respiratory disorders, diabetes, increased risk of infection, neurological problems including seizures, thyroid dysfunction, dementia (mental disorder characterized by confusion, disorientation, and memory loss) ([Reference](#))

### **Behcet's disease**

Symptoms of Behcet's disease include: aphthous stomatitis (inflammation of the mucosa of the mouth) with the lesions healing in a few days to a month, but recurring (similar genital lesions recur less frequently). Ocular symptoms include posterior uveitis, iridocyclitis, a transient hypopyon (pus in the anterior chamber of the eye), iritis, and chorioretinitis (inflammation of the choroid and retina). Skin hypersensitivity. Vascular involvement includes thrombophlebitis (venous inflammation) of the large veins and arterial closing and aneurysm (dilation of an artery). Heart problems include: abnormal heart rhythms, missed heartbeats, early heartbeats and inflammation of the heart muscle. The lesions of aphthous stomatitis may be found elsewhere in the gastrointestinal tract. Symptoms vary from mild gastrointestinal discomfort to ulcerative colitis or regional enteritis and malabsorption problems. Arthritis occurs in about two-thirds of patients. Severe fatigue and malaise is common. The central nervous system is affected in about 23% of all patients with the disease (which may result in seizures, confusion, strokes, memory problems or headaches). ([Reference](#)) ([Reference](#)) ([Reference](#))

### **Ulcerative colitis**

Symptoms of ulcerative colitis include: diarrhea or rectal urgency, rectal bleeding, bloody diarrhea and mucus, rectal pain and an urgent need to empty your bowels, abdominal pain, constipation, loss of appetite, fever, weight loss and fatigue. Ongoing (chronic) symptoms, such as diarrhea, can lead to weight loss, anaemia and also: joint pain, eye problems, skin rash, or liver disease. ([Reference](#)) ([Reference](#))

### **Kawasaki disease**

The first symptom usually is a sudden, high fever that may be 104 F or higher that can last more than 10 days if the disease is not treated. Other symptoms often occur within a few days after the fever. These symptoms include: red, bloodshot eyes, usually without pus or discharge, a red body rash that varies in size, shape, and consistency, red, swollen, cracked lips and a red ("strawberry") tongue and lining of the mouth, firm, swollen hands and feet with shiny red palms and soles and swelling of lymph nodes on one side of the neck. Other symptoms may include: irritability and tiredness, joint swelling and pain, abdominal pain, vomiting, and diarrhea, a rapid heart rate or changes in heart rhythm from heart inflammation. ([Reference](#))

### **Post-infectious polymyositis**

Symptoms of Polymyositis can include: weak, tired and painful muscles mainly affecting the large muscles of the body, such as those around the shoulders, hips, and thighs (causing difficulty climbing stairs, getting up from low chairs, and getting in and out of the bath), muscles tender to the touch, feeling generally unwell (malaise), weight loss, night sweats. ([Reference](#))

### **Vitamin B deficiency**

Symptoms of vitamin B deficiency can include: mental problems, heart palpitations, heart arrhythmias, indigestion, chronic fatigue, chronic exhaustion, paranoia, vague fears, fear that something dreadful is about to happen, nervousness, attention deficiency, inability to concentrate, irritability, feeling of uneasiness, thoughts of dying, easy agitation, frustration inability to sleep (insomnia), restlessness, tingling in hands fingers and toes, rashes, crying spells, inability to cope, soreness all over. ([Reference](#))

### **Rheumatoid illness or lupus (SLE)**

Symptoms of lupus can include: achy joints (arthralgia), frequent fevers of more than 100 degrees F., arthritis (swollen joints), prolonged or extreme fatigue, skin rashes, anemia, kidney involvement, pain in the chest on deep breathing (pleurisy), butterfly-shaped rash across the cheek and nose, sun or light sensitivity (photosensitivity), hair loss, abnormal blood clotting problems, raynaud's phenomenon (fingers turning white and/or blue in the cold), seizures, mouth or nose ulcers. ([Reference](#)) ([Reference](#))

### **Sarcoma**

Symptoms of Sarcoma include: joint swelling and tenderness, weight loss, fatigue, anemia, or pain without any clear source of injury, increasing abdominal pain, blood in stools or in vomit. ([Reference](#))

## **Toxoplasmosis**

Symptoms of Toxoplasmosis include: feeling off color, mild fever, enlarged neck lymph nodes, malaise, muscle pains, enlarged lymph nodes, enlarged glands, anemia, liver symptoms, low blood pressure, blood symptoms, eye symptoms, eye inflammation ([Reference](#))

## **HIV/AIDS**

Symptoms of early HIV infection can include: fever, headache, tiredness, nausea, diarrhoea and enlarged lymph nodes (organs of the immune system that can be felt in the neck, armpits and groin). Many people do not develop any symptoms when they first become infected with HIV. Some people, however, get a flu-like illness within three to six weeks after exposure to the virus. These symptoms usually disappear within a week to a month and are often mistaken for another viral infection. ([Reference](#))

## **Lyme disease (*Borrelia burgdorferi*)**

Symptoms of chronic Lyme disease can include: profound fatigue, unexplained fevers and chills, severe headache, severe muscle aches/pain, unexplained weight change (loss or gain), swollen glands, sore throat, unexplained sweats, night sweats, nerve conduction defects (weakness/paralysis of limbs, loss of reflexes, tingling sensations of the extremities - peripheral neuropathy), severe headaches, stiff neck, meningitis, cranial nerve involvement (e.g. change in smell/taste; difficulty chewing, swallowing, or speaking; hoarseness or vocal cord problems; facial paralysis - Bell's palsy; dizziness/fainting; drooping shoulders; inability to turn head; light or sound sensitivity; change in hearing; deviation of eyeball, stroke, abnormal brain waves or seizures, sleep disorders, cognitive changes (memory problems, difficulty in word finding, confusion, decreased concentration, problems with numbers), behavioral changes (depression, personality changes), panic attacks; disorientation; hallucinations; extreme agitation; impulsive violence, manic, or obsessive behavior (paranoia, schiziphrenic-like states), dementia, eating disorders, vision changes, including blindness, retinal damage, optic atrophy, red eye, conjunctivitis, "spots" before eyes, inflammation of various parts of the eye, pain, double vision, rash not at the bite site (this skin discoloration varies in size and shape; usually has rings of varying shades, but can be uniformly discolored; may be hot to the touch or itch; ranges in color from reddish to purple to bruised-looking; and can be necrotic (crusty/oozy). The rash may develop a bull's-eye rash or target look. The shape may be circular, oval, triangular, or a long-thin ragged line), irregular heartbeats, heart block, myocarditis, chest pain, vasculitis, intermittent or chronic joint pain (usually not symmetrical; sometimes swelling), TMJ-like pain in jaw, difficulty breathing, pneumonia. Shortness of breath, Cough, muscle pain and cramps, loss of muscle tone, nausea, vomiting, diarrhea, loss of appetite, anorexia. ([Reference](#))

## **Tuberculosis**

Early infection symptoms of tuberculosis include: fever, chills, sweating, night sweats, flu-like symptoms, gastrointestinal symptoms, weight loss, no appetite, weakness, fatigue. Symptoms of pulmonary tuberculosis include: persistent cough, chest pain, coughing up bloody sputum, shortness of breath, breathing difficulty, recurring bouts of fever, weight loss, progressive shortness of breath, cloudy urine or reddish urine. ([Reference](#))

## **Brucellosis**

Symptoms of Brucellosis include: Flu-like symptoms, fever, sweats, headaches, back pains, physical weakness, joint pain, enlarged liver, enlarged spleen, relapsing cycles of fevers. ([Reference](#))

## **Anxiety neurosis**

Symptoms of anxiety neurosis include: excessive anxiety and worry (apprehensive expectation), restlessness, easy fatigue, poor concentration, irritability, muscle tension (including trembling, twitching, feeling shaky, muscle aches, and soreness), disturbed sleep. ([Reference](#))

## **Depression**

Symptoms of depression include: abnormal depressed mood, loss of interest and decreased energy, loss of confidence, excessive guilt, recurrent thoughts of death, poor concentration, agitation or retardation, change in appetite, sadness, lethargy, helplessness, hopelessness, worthlessness, difficulties with decisions, changes to sleep patterns - difficulty sleeping or staying awake, changes in weight - either significant loss or gain in weight, relationship problems with partners, friends, family, colleagues, isolation, anxiousness, unusual fear or feeling panic. ([Reference](#))

## **PTSD**

The symptoms of PTSD include: severe fatigue, sleep problems including nightmares and waking early, flashbacks and replays which you are unable to switch off, impaired memory, forgetfulness, inability to recall names, facts and dates that are well known to you, impaired concentration, impaired learning ability (eg through poor memory and inability to concentrate), hypervigilance, exaggerated startle response, irritability, sudden intense anger, occasional violent outbursts, panic attacks, emotional hypersensitivity, joint and muscle pains which have no obvious cause, feelings of nervousness, anxiety, reactive depression, excessive levels of shame, embarrassment, survivor guilt, a feeling of having been given a second chance at life, undue fear, low self-esteem and shattered self-confidence, emotional numbness, anhedonia (inability to feel love or joy), feelings of detachment, avoidance of anything that reminds you of the

experience, physical and mental paralysis at any reminder of the experience.  
(Reference)

### **Schizophrenia and other psychiatric disease**

Symptoms of Schizophrenia include: delusions, hallucinations, disorganised thinking, disorganised behavior, catatonic behaviour, withdrawal, loss of motivation and ambivalence (Avolition) (this may involve lack of energy, apathy or seeming absence of interest in what were usually routine activities. People experiencing avolition may be inattentive to grooming, personal hygiene, have difficulty making decisions and have difficulty persisting at work, school or household chores), loss of feeling or an inability to experience pleasure (Anhedonia), poverty of speech (Alogia), flat presentation (Affective Flattening), cognitive impairments (including problems with attention, concentration and memory). (Reference)

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

1. **Diagnosis based on symptomatology only?** Assessing a patient's symptomatology is only one part of the process of diagnosis. Diagnosis cannot be and should not be made on the analysis of symptomatology alone (unless an illness, for example M.E., has symptoms or groups of symptoms which are unique to that one illness). Correct diagnosis must combine an analysis of the symptoms present with a thorough medical history, physical exam, and with appropriate testing. Unlike almost all of the illnesses listed here the onset of M.E. is *always* acute. So determining the type of onset – acute or gradual – is very important, for example. (See below for further information on the acute onset of M.E.) It is not appropriate to use these symptom lists alone to diagnose any illness. These lists are included merely to illustrate how easily many of these illnesses may be (and are) misdiagnosed as 'CFS.'
2. **M.E. is always an acute onset illness.** Most people with M.E. will know not only the exact week and day they became ill, but even the exact hour that they suddenly became ill. The onset of M.E. is frequently very dramatic and patients can usually be diagnosed within 2 weeks of the onset of their illness.

Arbitrarily separating those with acute onset illness to the M.E. category, and those with gradual onset to being in the 'CFS' category is problematic however because (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 bodies of those so affected somewhat more vulnerable to all types of infections, including M.E.)

M.E. must be diagnosed by looking at the patient's onset type, overall symptomatology, and pathology. If the symptomatology and pathology fit M.E. then it can only be M.E. regardless of the onset type noted (M.E. is a clearly defined disease process with several unique features/characteristics and known pathology), and either point (a) or point (b) will apply (Hyde 2006, [Online]) (Hyde 2007, [Online])

- 3. Similar illnesses?** Despite claims to the contrary by some groups, M.E. is not the same illness (or even almost the same illness) as Lyme disease, Fibromyalgia, Gulf War Illness (GWI), MCSS, various post viral fatigue syndromes caused by glandular fever/mononucleosis etc. or any other illness. While these illnesses may have some symptoms in common with M.E., so do many other different illnesses. M.E. also has several unique features and symptoms which are not seen in *any* of these illnesses (for example the fact it occurs in epidemic and sporadic forms, the unique post exertional muscle weakness and worsening with exercise, the strong links with polio and post-polio syndrome, and so on). Although there are some similarities between the symptoms seen in these illnesses to some extent this does not mean that they represent the same etiological or pathobiological process, share the same core and essential symptoms, or will have the same or even a similar response to treatment, the same pathology, or a similar prognosis. *They do not.*

The idea of these very different patient groups being mixed up and treated as if they represented the exact same patient group is truly alarming. The results could only be disastrous for all concerned. Just like each of these illnesses Myalgic Encephalomyelitis is a distinct and unique illness and it is vitally important that they are each always seen that way for the benefit of all patients involved. Patients with all of these illnesses must be correctly diagnosed and treated based on studies involving only the same patient group! There is nothing to be gained by joining these illnesses as if they each referred to the same or only slightly different patient group as this is simply not the case. We must not let another 20 years be wasted mixing together vastly different patient groups unnecessarily!

4. **I'm still confused... in a nutshell, what is the difference between M.E. and 'CFS'?** 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.*

**Chronic Fatigue Syndrome** is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis. Every diagnosis of 'CFS' can only ever be a misdiagnosis.

**Myalgic Encephalomyelitis** is a systemic neurological disease initiated by a viral infection. M.E. is characterised by (scientifically measurable) damage to the brain, and particularly to the brain stem which results in dysfunctions and damage to almost all vital bodily systems and a loss of normal internal homeostasis. Substantial evidence indicates that M.E. is caused by an enterovirus. The onset of M.E. is always acute and M.E. can be diagnosed within just a few weeks. M.E. is an easily recognisable distinct organic neurological disease which can be verified by objective testing. If all tests are normal, then a diagnosis of M.E. cannot be correct.

M.E. can occur in both epidemic and sporadic forms and can be extremely disabling, or sometimes fatal. M.E. is a chronic/lifelong disease that has existed for centuries. It shares similarities with MS, Lupus and Polio. There are more than 60 different neurological, cognitive, cardiac, metabolic, immunological, and other M.E. symptoms. Fatigue is not a defining nor even essential symptom of M.E. People with M.E. would give anything to be only severely 'fatigued' instead of having M.E. Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

M.E. is not synonymous with CFS, nor is it a subgroup of CFS. (There is no such thing as a subgroup of CFS; there is no such disease/s as "CFS.") M.E. is not a primarily fatiguing condition, nor is it a wastebasket diagnosis or 'medically unexplained' as 'CFS' is. Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. would achieve nothing and only create yet more

confusion and mistreatment. The problem is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually *do* have psychological illnesses. *There is no such distinct disease/s as 'CFS'* – that is the entire issue, and the vast majority of patients misdiagnosed with CFS *do not* have M.E. and so have no more right to that term than to 'cancer' or 'diabetes.' The only way forward, for the benefit of society and every patient group involved, is that:

1. The bogus disease category of 'CFS' must be abandoned completely.
  2. The name and definition of Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. (as a distinct neurological disease) must be accepted and adhered to in all official documentations and government policy.
- Patients with M.E. must again be treated for and diagnosed with M.E. based on research involving genuine M.E. experts and actual M.E. patients.

There is no such disease/s as 'CFS' – the name CFS and the bogus disease category of CFS must be abandoned (along with the use of other vague and misleading umbrella terms such as 'ME/CFS' 'CFS/ME' 'ME-CFS' 'CFIDS' and 'Myalgic Encephalopathy' and others), for the benefit of all the patient groups involved, as well as the medical community and the general public.

- For more information see: Who benefits from 'CFS' and 'ME/CFS'?, The Terminology Explained, Why the disease category of 'CFS' must be abandoned, Myalgic Encephalomyelitis is not fatigue, or 'CFS' and What is M.E.?
5. **I seem to fit the 2003 Canadian definition of 'ME/CFS' does this mean that I have M.E.?** No, it doesn't. As the name suggests, this is a mixed M.E. and 'CFS' definition. It is essentially yet another redefinition of CFS, but with some of the symptoms (and other features) of M.E. tacked on. The Canadian 'ME/CFS' definition should not be considered a pure M.E. definition as it is easily possible to qualify for the diagnosis *without* having the unique and essential features of M.E.
- For more information see: Where to after a 'CFS' (mis)diagnosis? (Question and answer session)
6. **Dual diagnosis?** Despite the fact that severe pain is a well known and very common symptom of M.E. many M.E. sufferers who have pain are told that they now also supposedly have 'Fibromyalgia.' But if pain is a recognised symptom of M.E. then how does an additional Fibromyalgia diagnosis made purely on the presence of pain make sense? Patients who have Fibromyalgia

and patients with primary M.E. can be easily distinguished from each other with various tests (and other means including an evaluation purely based on symptomatology which is very different between the two illnesses), so what do tests show in patients who supposedly have both? Interestingly, when patients (supposedly) have both illnesses the test results given are the ones for M.E. *only*. So do these M.E. patients really also have Fibromyalgia, or do they just have severe pain as part of their M.E.? As you might expect, these test results strongly suggest the latter.

The same is true of multiple chemical sensitivity syndrome (MCSS); symptoms of chemical sensitivity are part of the core symptoms of M.E. and have long been associated with M.E. (as well as with several other autoimmune illnesses such as multiple sclerosis and Lupus) and so there is no need for an additional diagnosis of MCSS to be made. This additional diagnosis is incorrect. Just because you may fit a definition of Fibromyalgia, or MCSS, or irritable bowel syndrome (IBS) this does not mean that your symptoms are caused by the same etiological or pathological process, or will respond to various treatments the same way, or will have the same prognosis as those people who have primary Fibromyalgia, MCSS or IBS, and so on. All of these symptoms from pain to chemical sensitivities to constipation or diarrhoea are all very common symptoms of M.E. making additional diagnoses inappropriate.

- See [M.E. and other illnesses](#) and [ME vs Fibromyalgia](#) for more information. See also the new paper: [M.E. vs MS: Similarities and differences](#)
- See: [What is M.E.?](#) for more information on all aspects of M.E. (and ‘CFS’)

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*“People in positions of power are misusing that power against sick people and are using it to further their own vested interests. No-one in authority is listening, at least not until they themselves or their own family join the ranks of the persecuted, when they too come up against a wall of utter indifference.”*  
Professor Hooper 2003

*‘Thirty years ago when a patient presented to a hospital clinic with unexplained fatigue, any medical school physician would search for an occult malignancy, cardiac or other organ disease, or chronic infection. The concept that there is an entity called chronic fatigue syndrome has totally altered that essential medical guideline. Patients are now being diagnosed with CFS as though it were a disease. It is not. It is a patchwork of symptoms that could mean anything’* Dr Byron Hyde 2003

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

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

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

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- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were ‘atypical multiple sclerosis’ and ‘atypical polio.’
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation’s International Classification of Diseases since 1969 as a distinct organic neurological disease.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.

However, the hearts of M.E. patients only barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.

If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.

*M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.*

- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

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