

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.**

- Part 2 of this paper (included in the full-length version of this text) 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 also Where to after a 'CFS' (mis)diagnosis?
- For information on how authentic M.E. is characterised and diagnosed see: Testing for Myalgic Encephalomyelitis and What is Myalgic Encephalomyelitis?
- For more information please see The misdiagnosis of 'CFS' at www.hfme.org.



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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' - Summary

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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 illness named 'CFS.' **A diagnosis of CFS – based on any of the 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.' 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 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 as 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’ (or ‘CFS’) only hinders each of the patient groups involved in their battle to regain their health.

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:

- Missed cardiac disease,
- Missed malignancy,
- Missed vascular disease,
- Missed brain lesion either of a vascular or space occupying lesion,
- Missed test positive rheumatologic disease,
- Missed test negative rheumatologic disease,
- Missed endocrine disease,
- Missed physiological disease,
- Missed genetic disease,
- Missed chronic infectious disease,
- Missed pharmacological or immunization induced disease,
- Missed social disease,
- Missed drug use disease or habituation,
- Missed dietary dysfunction diseases,
- 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 and/or ‘Burnout’
- Multiple chemical sensitivity syndrome (MCSS)
- Multiple sclerosis or Transverse Myelitis
- Thyroid illness or adrenal insufficiency
- Localised and Metastatic malignancies
- Brain tumours, including astrocytomas, gliomas
- 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 or 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]) (Hyde 1992, p 22) (Dowsett n.d.a. [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 (mis)diagnosis by default (due to the ignorance surrounding M.E., and the confusion with ‘CFS’). Therefore the possibility that a patient misdiagnosed with CFS has authentic Myalgic Encephalomyelitis should also be investigated, where appropriate.

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 heterogenous 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 heterogenous 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])