

Myalgic Encephalomyelitis: A legal guide to the perplexed

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Introduction

In 1994 Flemming, a British doctor who had retired because of Myalgic Encephalomyelitis (ME) stated, "medical training had not equipped me to understand ME".¹ Fortunately, especially for patients, knowledge has grown with time. A number of other names have been used for this condition most notably Chronic Fatigue Syndrome (CFS), the term preferred by the majority of doctors and researchers.² The condition affects young children, adolescents, men and woman of all age groups, social backgrounds and ethnic groups.³ The condition is recognized by at least the following influential people/bodies: Commissioner of Social Security in the United States The World Health Organization, The United Kingdom Department of Social Security, The United Kingdom Department of Health, The Royal Colleges of Physicians and The Centers for Disease Control and Prevention in Atlanta. In 1994 Flemming, a British doctor who had retired because of Myalgic Encephalomyelitis (ME) stated, "medical training had not equipped me to understand ME".¹ Fortunately, especially for patients, knowledge has grown with time. A number of other names have been used for this condition most notably Chronic Fatigue Syndrome (CFS), the term preferred by the majority of doctors and researchers.² The condition affects young children, adolescents, men and woman of all age groups, social backgrounds and ethnic groups.³ The condition is recognized by at least the following influential people/bodies: Commissioner of Social Security in the United States The World Health Organization, The United Kingdom Department of Social Security, The United Kingdom Department of Health, The Royal Colleges of Physicians and

The Centers for Disease Control and Prevention in Atlanta.

Criteria

Because of etiology-based modifiers and variable symptom profiles that fluctuate, interested parties have had difficulty in setting a case definition for a diagnosis of ME. However, there are significant associations between the criteria identified by the different interested parties.

In an attempt to achieve consensus on the criteria for ME the CDC in April 1987 convened a panel with the express brief to establish a consensus definition of "CFS".⁴ The panel suggested a set of criteria that was purposefully restrictive to maximize the chance of significant associations.⁵

In 1994 the Centers for Disease Control and Prevention convened a second panel for this purpose.⁶ The panel modeled a revised case definition for CFS on the 1988 definition also taking into account the other key international definitions in use at the time. In terms of the revised definition a case of CFS is defined by: *Clinically evaluated, unexplained, persistent or relapsing chronic fatigue. The fatigue must be of a new or definite onset (has not been lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest and results in substantial reduction in previous levels of occupational, educational, social, or personal activities.*

The requirement of below 50% daily activity was dropped. The concurrent presence of four or more of the following symptoms which persisted or recurred for at least 6 months:

1. Self-reported impairment of short-term memory or concentration severe enough to cause substantial

reduction in previous levels of occupational, educational, social or personal activities

2. Sore throat
3. Tender cervical or axillary lymph nodes
4. Muscle pain
5. Multijoint pain without joint swelling or tenderness
6. Headaches a new type, pattern or severity
7. Unrefreshing sleep
8. Post exertion malaise lasting more than 24 hours

The requirement of 6 months duration was retained to facilitate comparison with earlier cases of CFS.⁷ All physical signs were dropped from the criteria. A set of exclusion criteria for psychiatric comorbidity was suggested. In terms of the revised definition the following clinical diagnoses excluded a finding of CFS:

- Any active medical condition that could explain the chronic fatigue.
- Any previously diagnosed medical condition whose resolution has not been documented beyond reasonable clinical doubt and whose continued activity may explain the chronic fatiguing illness.
- Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders, schizophrenia; delusional disorders, dementias, anorexia nervosa, bulimia nervosa.
- Alcohol or other substance abuse within 2 years prior to the onset of the chronic fatigue and any time afterward.

The CDC definitions, especially the 1994 definition have to a lesser or larger extent been used by many interested parties as research or operational definitions.

However, these interested parties also point to a wide range of other associated symptoms. I refer to a few other interested parties.

On 30 April 1999 the Commissioner of Social Security in the United States of America essentially accepted the diagnostic symptoms in the revised CDC consensus definition in his policy statement regarding CFS.⁸ In terms of the statement "CFS" is a systemic disorder consisting of a complex of symptoms that may vary in incidence, duration and severity. Other symptoms include muscle weakness, swollen underarm (axillary) glands, sleep disturbances, visual difficulties more specifically trouble focusing or severe photosensitivity, orthostatic intolerance for example lightheadedness or increased fatigue with prolonged standing, other neurocognitive problems for example difficulty comprehending and processing information, fainting, dizziness and mental problems for example depression, irritability and anxiety. No reference was made to the exclusion criteria.

In 2001 the South African Medical and Underwriting Standing Committee, Life Offices Association of South Africa tabled the following symptoms for "CFS": fatigue; difficulty concentrating; headache; sore throat; tender lymph nodes; muscle aches; joint aches; feverishness; difficulty sleeping; psychiatric problems; allergies; abdominal cramps; weight loss; rash; rapid pulse; weight gain; chest pain; night sweats.⁹ They indicate that the symptoms may vary in intensity, but are generally activated by stress and exertion.

In 2002 Richardson found the central feature of the syndrome in the way that the symptoms manifest themselves.¹⁰ She states that the illness can have a prolonged relapsing and remitting course over months and years with the energy levels and symptoms fluctuating day-to-day or week-to-week. Symptoms are characteristically provoked by increased mental or physical activity. She found the common symptoms to include: persistent fatigue; post-exertional malaise, which can include flu-like symptoms; painful or aching muscles or joints with or without muscle twitching; nerve pains/pins and needles; headaches/migraines; cognitive impairment including reduced attention span, short term memory problems, difficulty finding words and disorientation;

sleep disturbance including unrefreshing and restless sleep, early waking, insomnia and hypersomnia; other nervous system symptoms such as poor temperature control; dizziness on standing up, balance problems and increased sensitivity to light and sound; recurrent sore throat; digestive disturbances such as nausea, loss of appetite, indigestion, excessive wind, bloating, abdominal cramps and alternating diarrhoea and constipation.

Etiology and treatment

The pathogenesis and pathology of this condition is still controversial and its treatment unclear. Many causes of ME including infectious agents such as viral infections, disruption of the immune system, toxic exposure and neuroendocrine dysfunction have been suggested. It now seems clear that the condition can be triggered by at least the first two causes mentioned and that the persistence of the viral infection is not necessary to maintain the condition. ME is an organic disease and any psychosocial aspects can be regarded as consequential rather than causative. There is no known cure or universally successful treatment and therapies are aimed at alleviating the symptoms.

Disability

CFS patients suffer significant long-term functional impairment. This fact is well documented and substantiated by several long-term evaluations of the life impact of CFS. Again I mention but a few of these evaluations. In 1996 Jason *et al* published their findings on patients with CFS.¹¹ They found that many individuals are forced to surrender their occupations and basic tasks such as grocery shopping, cleaning and cooking may become unmanageable. As a result of this they become housebound and isolated from others. The results of a study by Buchwald *et al* regarding the functional status of 185 patients with ME were also published in 1996.¹² The mean age of the subjects was 39 and the level of education was high. Patients were seen in a university-based referral clinic and all the patients had undergone a complete medical and psychiatric evaluation. The Medical Outcomes Study Short-Form General Health Survey (SF 36)¹³ and a structured psychiatric interview were used. The study found CFS patients even in comparison with medically-ill populations strikingly

disabled. For example the role functioning subscale scores for patients with congestive heart failure and myocardial infarction are typically over 50.¹⁴ In comparison the CFS patients scored only 3. The study found the impairment of CFS patients across all functional domains greater than that observed for any other medical or psychiatric disorder. The average duration of the illness was found to be 4.7 years. 54% of patients were not employed part- or full-time at follow up.

In 2004 Anderson *et al* published their evaluation of the life impact of CFS on 33 adult patients over 5 years in 2004.¹⁵ All 33 patients met the 1988 and 1994 CDC criteria. In 1994 work disability was 77%. By 1999 it had increased to 91%. At follow up no patient was in full-time or regular employment. One patient was in part-time supported employment. Two were part-time students and one patient was self-employed less than full time. Housework disability remained the same at follow up at around 55%. Social impairment remained high at follow up. One participant in the study was near recovery and another was substantially better but still severely disabled. In conclusion Anderson *et al* found CFS patients to exhibit severe long-term functional impairment and that substantial improvement is uncommon at less than 6%. ♡

References

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