

# Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

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## Abstract

ME/CFS is a debilitating condition hardly discussed in the Maltese Islands, and was only recognized in 2009 as a neurological disease in our archipelago despite it being recognized by WHO in 1969. The authors discuss the origin of the combined terminology ME/CFS, the importance of recognizing the condition at an early stage, the appropriate treatment and the potential role of the health services. The authors also highlight the lack of official statistical data available in the Maltese archipelago.

## Keywords

Malta, ME/CFS, terminology, treatment, health service.

## Introduction

ME/CFS is a debilitating, chronic, acquired disease characterized by a range of disturbances effecting all body systems, but predominantly the neurological, endocrine and immune systems. Following normal physical or mental activity, ME/CFS sufferers experience profound fatigue, exhaustion, loss of muscle power, pain, joint tenderness and cognitive dysfunction.

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Other conditions should be excluded such as sleep apnea, anemia, unresolved infections such as hepatitis B or C, side effects of medications and other major depressive disorders. (ICD-9-CM, 2011).

## The Terminology Crisis

Since 1969, ME/CFS has been classified as a neurological disorder in the World Health Organisation (WHO) International Classification of Diseases (ICD 10 G93.3).

The combined terminology: ME/CFS has in-depth history and is still a grey area as many doctors are unsure which terminology to use.

However, in October 2011, Carruthers rejected the term CFS and stated that:<sup>5</sup>

*'In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term 'myalgic encephalomyelitis' (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization's International Classification of Diseases (ICD G93.3).'*

Despite this, many practitioners opt to make do with the combined terminology, to prevent misunderstandings within the medical, research and patient community, avoiding confusion within medical health care.

## Epidemiology

Carruthers reported that the prevalence ranges from 0.4% to 2.5% worldwide, around 235-700 per 100,000 individuals, more prevalent than AIDS, lung or breast cancer.<sup>2</sup>

There is no current epidemiological data for the local Maltese Islands, despite the 800 sufferers living in the archipelago according to a local newspaper published in 2009. This was found to be confirmed by Dr. John Greensmith, representing 'ME Free For All' U.K based organization who obtained this calculation through foreign statistics in 2009.

Until 2011, Malta did not recognize ME/CFS as a disability despite the syndrome enlisted as a neurological disorder by WHO.<sup>10</sup>

### The Aetiology of ME/CFS and the relevant risk factors

The aetiological causes of ME/CFS are topics of vigorous research and debate due to the multi-factorial pathogenesis (Figure 1). The scientific community has not yet identified the cause but suggest a variety of factors which can be classified into two:

- a. Predisposing factors
- b. Events that stress the immune system and prompt onset

#### A. Predisposing factors

According to Shepherd genetics, gender, age and psychological factors are the crucial predisposing factors.<sup>20</sup> The psychological factors are mainly excessive stress, a study carried out by Bentall indicate the presence of a stressful event experienced by one-third of the patients prior to the onset of disease.<sup>37</sup> The study conducted by Bell has shown that women are more vulnerable to ME/CFS and three-fourths of the sufferers develop the condition in the mid-40 age group.<sup>10</sup>

#### B. Events that stress the immune system and prompt onset

ME/CFS frequently follows an acute infection such as an upper respiratory infection, amongst others. However, there is no conclusive evidence for the latter with no specific pathogen. Carruthers argues that the following are thought to related:<sup>2</sup>

- Epstein-Barr Virus
- Human Herpesvirus-6 and 7
- Enterovirus
- Cytomegalovirus
- Lentivirus
- Chlamydia
- Mycoplasma

### Clinical Features

Physical and emotional fatigue is the main clinical symptom, which lasts for more than 24 hours and is not treated with sleep. This causes loss of concentration, short term memory loss and muscle pain. Headaches and sore throats are frequent accompanying symptoms and usually persist for 6 months or more (Figure 1).

### Investigations

There is no single diagnostic test for ME/CFS, and testing is done to exclude other organic causes for the clinical features. Blood test may include checking the levels of creatinine kinase to exclude a myopathy. This may further be supported with an electromyogram. EEG studies have revealed particular characteristics pertinent to ME/CFS in children even though such evidence has yet to be further evaluated.<sup>29</sup>

### Treatment

'In my experience, CFS is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages.'<sup>15</sup>

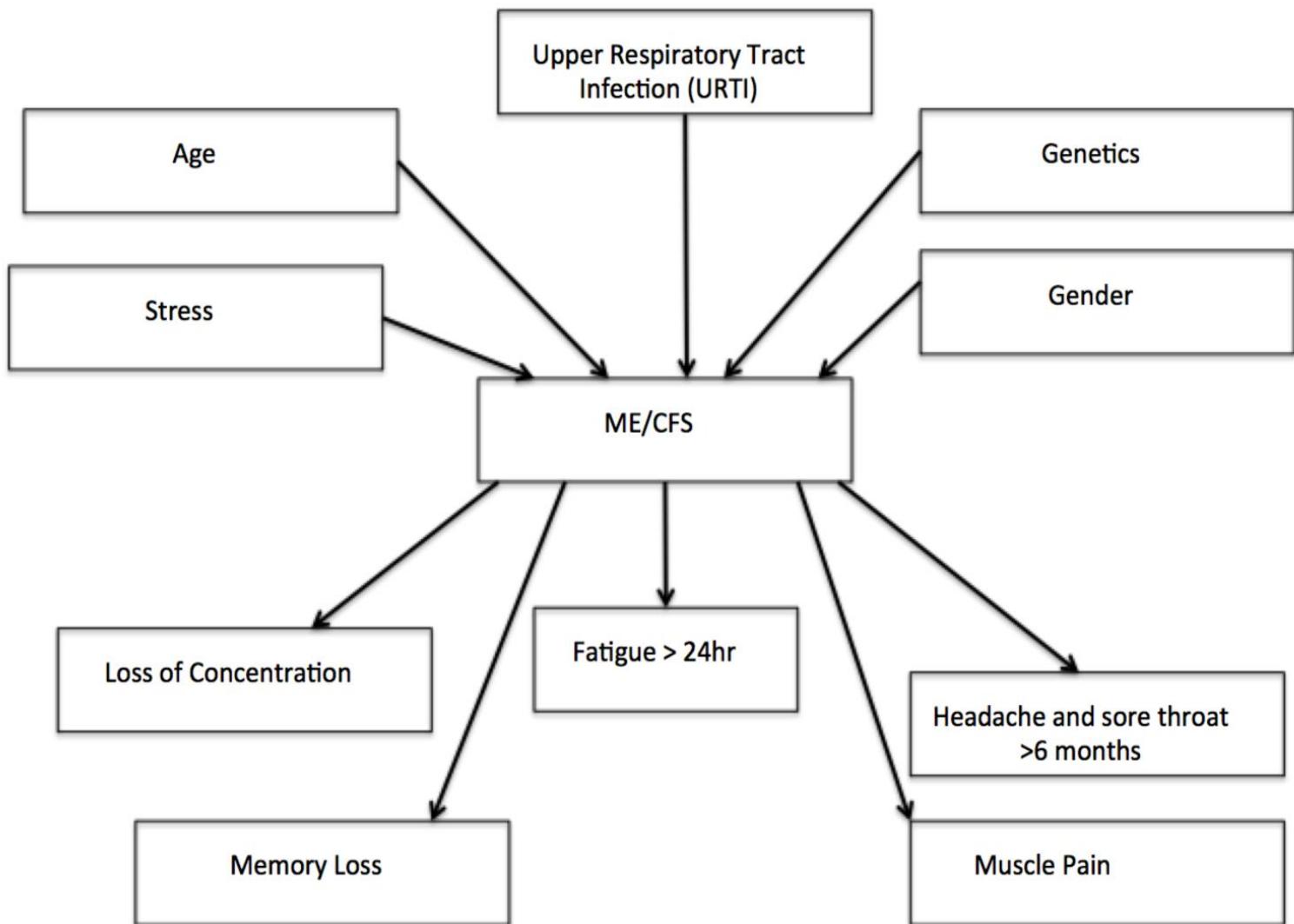
Muscle symptoms are common in ME/CFS patients, prompting research regarding the disturbance of carnitine homeostasis. According to Evans *et al.* this may possibly be due to a decreased carnitine palmitoyltransferase-I (CPT-I) activity and accumulation of omega-6 fatty acids.<sup>30</sup> Hence, possibly an increase intake of omega-3 fatty acids and L-carnitine will increase CPT-I activity, improving symptoms.

Perrin *et al.* suggests that 'Perrin Technique', an osteopathic intervention may be the key to future treatment whereby findings suggest that many of the symptoms experienced by ME/CFS patients are due to a lymphatic drainage disturbance.<sup>29</sup> The 'Perrin Technique' stimulates toxin drainage out of lymphatic system into the blood, which are then detoxified by the liver (Figure 2). This results in a decrease toxin level within the cerebrospinal fluid and hence improved symptoms.

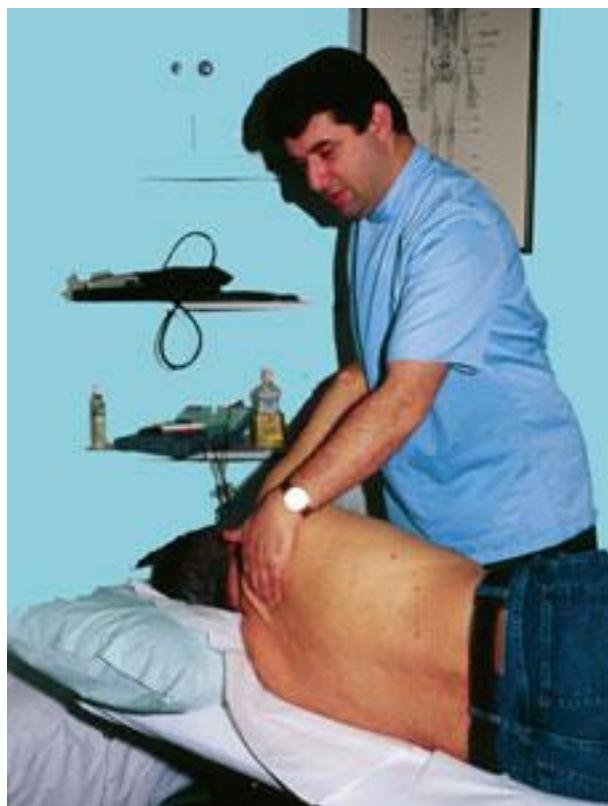
Holtorf reported that ME/CFS patients have a reduced cortisol output and hypothalamic-pituitary-adrenal axis hypofunction which causes the fatigue.<sup>15</sup> Cortisol treatment should be part of the multi-system treatment program for ME/CFS individuals.

Further research is required to locate the site of abnormality in brainstem perfusion which Costa *et al.* reported a decrease in ME/CFS patients.<sup>3</sup> This may explain why patients experience cognitive dysfunction, the typical 'brain fog'.

**Figure 1:** Summary of factors contributing to ME/CFS and the clinical features of the condition.



**Figure 2:** The 'Perrin Technique'. A therapy recommended by Perrin *et al.* which causes toxin drainage from the lymphatic system.<sup>35</sup>



### The Role of Health Services

In Malta, issues relating to ME/CFS are hardly discussed, with very few individuals within the community aware about the condition.

To date there is no specific treatment for ME/CFS apart from pharmacological therapy to alleviate symptoms. However, a CFS/ME Multidisciplinary team should be set up and available to all individuals suffering from the disorder on the island, rather than patients seeking treatment regimens internationally.

This group will increase the awareness of CMS/ME and develop group and individualized therapeutic options for sufferers by:

- Offering a rehabilitation program which advises patients on energy and anxiety management.
- Advising patients how to overcome psychological obstacles, how to maintain a well balanced diet despite their numerous sensitivities
- Setting up a lifestyle management program designed by occupational therapists, which advises patients on work simplification techniques.
- Adequate pharmacological treatments to alleviate the numerous symptoms patients experience.
- Providing professional Adaptive Pacing Therapy (APT), Graded exercise therapy programs (GET) and Cognition Behaviour therapy (CBT).

According to McCrone *et al.* the PACE trial

compared the four main treatments: general advice about management, APT, CBT and GET available for ME/CFS patients, and found CBT as the most cost-effective from a health care perspective.<sup>8</sup>

The lack of CFS/ME services will pose a problem to individuals who suffer from this disorder who without appropriate local services, will increase the incidence of the disease within the Maltese islands.

Thus, with adequate awareness, knowledge and health services, ME/CFS individuals may become productive citizens within the community. This will benefit themselves and society.

### Conclusion

ME/CFS is a disorder characterized by numerous systemic symptoms which severely impacts the quality of life, equivalent to late stage AIDS.<sup>19</sup> A few patients recover whilst others are left permanently debilitated.<sup>32</sup> Although CBT was found to be the most cost-effective therapy for ME/CFS, there is no specific cure and hence is a disorder which is being thoroughly researched. Regarding the local status in the Maltese islands, a multi-disciplinary team should be developed, for adequate treatment and management. More educational awareness within the medical community should be provided as this prevents late and incorrect diagnoses. This will prevent any possible sources of error in future epidemiological studies.

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