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**The ‘all in the mind’ myth of myalgic encephalomyelitis/chronic fatigue syndrome**

**Dr Keith Geraghty**

Health professionals should be made aware that ME/CFS is not a psychological illness and in order to improve patient care, nurses need to better understand this illness and its impact on patients.

Nurses often witness close-up the impact of acute and chronic illness on patients. Myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) is one illness that nurses may encounter that causes profound life changes for many sufferers. This controversial illness is sometimes presented as a psychosomatic disorder that requires psychological treatment. However, there is no compelling evidence that ME/CFS is a [mental health](http://www.nursinginpractice.com/mental-health-resource-centre) condition and increasing evidence shows it is a biological disease with a range of complex symptoms. This article discusses how the ‘all in the mind’ myth of ME/CFS has permeated both medical discourse and popular culture, with negative consequences for patients living with this poorly understood condition.

**1. Is ME/CFS really a mental illness?**

In a recent *Nursing in Practice* article, Roberts (2016)1 suggests that ME/CFS is a psychosomatic disorder, best treated with psychotherapy and mindfulness. The erroneous idea that mindfulness is an optimum treatment masks a hidden and more important story; that very little is understood about ME/CFS and many health professionals are skeptical about whether ME/CFS is even a real illness. For example, NICE guidelines do not mention mindfulness.2 A GP once exclaimed to me that ‘all these patients need is anti-depressants and a good pair of running shoes’. While discussing my ME/CFS research at a hospital in Leicester a nurse offered me a similar opinion by suggesting that ‘ME/CFS patients would get out of bed if you paid them £5000 per day’. Such negative views among doctors and nurses are not uncommon and are perhaps fueled by misinformation about the illness being psychological.

In a recent book, *All in Your Head: True Stories of Imaginary Illness,*3 Dr Suzanne O’Sullivan, a London-based consultant neurologist, includes a chapter on ME/CFS. O’Sullivan argues ME/CFS is strongly associated with psychological complaints and illness beliefs. In contrast, a growing body of scientific evidence suggests that ME/CFS is not an imagined illness, nor is it a psychological condition, but a complex biological disease that is often triggered by an infection that causes observable neuro-immune dysfunction. Far from being ‘all in the mind’, sufferers often experience life-changing and disabling physical symptoms and physiological abnormalities (see Table 1).

**Table 1: Biological abnormalities observed in ME/CFS**

·      Alterations in grey and white brain matter.

·      Muscle cell dysfunction.

·      Immune cell abnormalities.

·      Raised inflammatory markers.

·      Cellular and oxidative stress.

·      Autonomic irregularities.

·      Cardiovascular deficiencies.

·      Orthostatic intolerance.

The World Health Organization (WHO) classifies ME as a neurological disorder in the International Classification of Diseases (ICD-10: G 93.3; WHO, 1992).4

     The US Institute of Medicine (2015) conducted an extensive review of the evidence and concluded that ME/CFS is ‘a serious, chronic, complex, systemic disease’.5

     The US National Institutes for Health confirmed ME/CFS as a disabling physical illness and stated that the medical profession has been responsible for causing distress to patients with ME/CFS by ignoring patients’ calls for medical help and failing to adequately research the disease.6

**2. So why is ME/CFS treated with psychotherapy?**

Psychiatrists have long been interested in attempting to explain the medically unexplained. Sigmund Freud, the father of modern psychiatry, explored the connection between the mind and health. The famous French neurologist J. Charcot believed traumatic life events may bring about a form of hysteria or paralysis in patients; while George Beard put forward the theory of neurasthenia (exhaustion of energy within the nervous system).7 These theories continue to influence how doctors perceive medically unexplained illnesses, particularly ME/CFS.

**A brief time-line of how ME (nuero-immune disease) became CFS (a psychosomatic fatigue syndrome)**

·      1955: Melvin Ramsay describes a viral outbreak illness among staff at the Royal Free Hospital in London as a post-infectious disease affecting brain, nerves and muscle tissue (Myalgic Encephalomyelitis).

·      1970s: UK psychiatrists McEvedy and Beard state that ME is nothing more than a case of ‘mass hysteria’.

·      1980s: A London newspaper runs a story about ME being ‘Yuppie Flu’. Since then, ME has been indelibly linked with stressed-out professionals complaining about exhaustion.

·      1988: The US Centers for Disease Control recommend replacing ME with a new syndrome (Chronic Fatigue Syndrome).

·      1990s: UK psychiatrist Simon Wessely argues ME (now CFS) is a biopsychosocial syndrome, partly created by social trends and maintained by patients’ illness beliefs and behaviours.

·      2000s: Colleagues of Wessely, including nurse/researcher Professor Trudie Chalder, conduct clinical trials of psychotherapy to treat CFS, including the £5 million PACE trial testing cognitive behavioural therapy and graded exercise therapy.8

·      2007: The UK National Institute for Health and Care Excellence (NICE) conducts a review and recommends CBT and GET for the treatment of ME/CFS.2This decision is criticised by ME/CFS patient groups who deem CBT and GET inappropriate treatments. In particular, GET attracts much criticism.

·2015: A large patient survey finds CBT has little impact on the condition: 74% of patients report that GET makes their symptoms worse, while simple pacing is preferred by patients.9 Such concerns are echoed in scientific studies that suggest exercise therapy may be harmful, given biological abnormalities found in ME/CFS.10

**3. So, does cognitive therapy or exercise therapy help anyone with ME/CFS?**

The answer to this question is rather complex. ME/CFS is an umbrella term often used for patients with ongoing unexplained fatigue. Hooper (2006) points out that ‘Amorphous definitions and diagnostic symptom criteria have contaminated study cohorts and corrupted research data’.11Essentially, it may be difficult to differentiate patients with ME/CFS from patients with fatigue or depression, given the generality of the diagnostic criteria for CFS: patients are often lumped together in studies, with depressed patients responding better to CBT compared with ME/CFS patients.12 In addition, CBT may help with the secondary depression or anxiety that occurs in most illness states. Clinical trials of CBT and GET tend to recruit mild to moderately unwell CFS patients, as more severe cases are too unwell to take part. Yet, even if we accept these research biases, the evidence for the success of psychological or exercise therapies in ME/CFS is unconvincing:

·      **Cochrane review:**A meta-analysis found that while CBT and/or GET may benefit some patients with ME/CFS in the short term, the benefits are short-lived and have little impact on restoring physical function over the long term.13

·      **PACE trial:**The largest clinical trial of CBT and GET for CFS reported that 22% of patients recovered following CBT/GET added to standard care, while only 7% did after standard care alone.14 However, ‘recovery’ here did not mean a return to normal physical function. A patient could be deemed recovered with a SF-36 (quality of life) score of 60/100 or higher,8 even though a score of 65/100 indicates severe disability with 57/100 being a score of patients with Class II congestive heart failure.15 At follow-up, two years after treatment, there was no clear benefit of adding CBT or GET to standard medical care.8

·      **FINE trial:**A study of nurse-provided community-based CBT and GET for 296 CFS patients failed to find any evidence for the long-term effectiveness of these therapies.16FINE stood for ‘Fatigue Intervention by Nurses Evaluation’. CBT-GET was compared against a supportive listening treatment. The FINE investigators found no statistically significant benefits to either pragmatic rehabilitation (CBT-GET) or supportive listening at 70 weeks. The authors concluded that the community setting was inappropriate, rather than the psychotherapy treatment.

**4. Why is it important to know the facts?**

In a recent Centers for Disease Control ‘Grand Rounds’ event (2016) discussing ME/CFS research, Professor Anthony Komaroff of Harvard University stated that the medical profession were wrong to adopt the name Chronic Fatigue Syndrome in 1988, as this term led to inaccurate perceptions of the illness. Komaroff points out that that there are thousands of published articles on biological dysfunction in ME/CFS, with no compelling evidence to suggest the illness is psychogenic (an illness of the mind).16

     Many ME/CFS sufferers and advocacy groups are deeply concerned about the portrayal of the disorder as a psychological illness in medical publications and the wider media. Misinformation may negatively impact patients. Patient surveys consistently reveal that many ME/CFS patients experience medical scepticism, difficult interactions with health professionals and poor care quality (AfME, 2001).17 Sufferers report finding it difficult accessing benefits and social care and often have to fend off accusations of laziness and hypochondria – perhaps a consequence of the perception that the illness is a self-generated psychological illness.

     The 25% ME Group, a charity that supports the most severely ill sufferers, state that the medical establishment has largely ignored these ME/CFS patients.18 Many are housebound or bedbound, with [family](http://www.nursinginpractice.com/family-health-resource-centre) members as full-time care-givers.

     We must consider the harrowing case of Miss Sophia Mirza, a young ME sufferer forcibly removed from her home and sectioned under the Mental Health Act to impose psychiatric treatment on her. Miss Mirza died in 2005 and is one of the first patients in the UK to have ME as the official cause of death. The reality that ME/CFS kills some patients and dramatically shortens life expectancy is rarely reported in the media. In addition, ME/CFS sufferers are six times more likely to commit suicide compared to the general population;19 most likely as the result of having to deal with debilitating symptoms, such as chronic pain and sleep deprivation, but perhaps also having to deal with feelings of social isolation and poor medical treatment.

**5. What can nurses do to support ME/CFS patients?**

Many nurses will encounter ME/CFS patients, particularly in primary care. Nurses often have the capacity to form close therapeutic relationships with patients. Offering empathy and understanding to patients experiencing distressing symptoms is a central part of the nursing role. In the absence of a cure for ME/CFS, nurses are well placed to provide supportive care. By understanding the symptoms generated by the illness, nurses may be able to offer patients better care. ME/CFS severity varies from mild to severe and patients experience the illness in different ways. Some sufferers may be able to continue work on a limited basis, while others may be bed-bound, reliant on family and carers. Retired nurse Greg Crowhurst, a care-giver to a wife with severe ME/CFS, writes eloquently about how nurses may support patients with the illness.19

Practical tips for nursing practice are as follows:

·      Sufferers experience profound fatigue – nurses may be able to ensure patients are not left in waiting areas for long periods of time.

·      Sufferers experience cognitive problems – nurses may assist patients in medical consultations, perhaps asking whether the patient understands the information provided.

·      Sufferers experience sensory overload – nurses may ask patients if they require a quiet area or darkened room, or on home visits, nurses may avoid causing sensory distress by speaking quietly and ensuring mobile phones are turned off.

·      Sufferers symptoms vary and fluctuate – nurses should liaise with family members or care-givers to get a personalised account of the patient’s health status and care needs.

·      Sufferers often feel disbelieved and anxious – nurses may reassure patients, particularly if they convey empathy and knowledge of the illness to the patient.

Nurses also have an another important role as advocates for ME/CFS patients, helping to liaise between the patient and doctor and also helping to promote the patient voice in the public domain. However, to fulfill this important role, nurses need to better understand the illness and to understand that ME/CFS is by no means ‘all-in-then-mind’.

**Conclusion: The key message for nurses**

Most people feel fatigued following illness, stressful events, or after working long hours. This is quite different from the severe fatigue and the range of symptoms that patients with ME/CFS endure, including: unrelenting painful joints and muscles; cognitive dysfunction, including memory problems; gastrointestinal complaints; transient paralysis; hypersensitivity to light, noise and touch; unrefreshing sleep; post-exertional malaise after minimal effort; and the inability to maintain an upright posture for any significant period. Overwhelming evidence shows that these symptoms are not psychosomatic. Nurses have a valuable role to play in assisting and supporting patients with ME/CFS. Nurses should not underestimate the power and importance of the nursing position to relieve suffering, prevent harm and promote better care for ME/CFS patients.

**References**

1. Roberts D. Diagnosing and managing chronic fatigue syndrome. *Nursing in Practice* 2016, 89.

2. NICE. *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) - Diagnosis and management of CFS/ME in adults and*[*children*](http://www.nursinginpractice.com/family-health-resource-centre). NICE 2007, 53. <https://www.nice.org.uk/guidance/cg53/chapter/1-guidance>.

3. O’Sullivan S. *All in Your Head: True Stories of Imaginary Illness*, 2016.

4. WHO. *International Classification of Diseases, Tenth Revision (ICD-10)*. WHO 1992; G93.3.

5. IOM (Institute of Medicine). *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: redefining an illness*. Washington, DC; 2015. ISBN: 978-0-309-31689-7.

6. Green CR, Cowan P, Elk R, O'Neil KM, Rasmussen AL. National Institutes of Health pathways to prevention workshop: Advancing the research on Myalgic Encephalomyelitis/chronic fatigue syndrome. *Annals of Internal Medicine*2015;16;162(12):860-865.

7. Beard G. Neurasthenia, or nervous exhaustion. *The Boston Medical and Surgical Journal* 1869;217-221.

8. White PD, Goldsmith KA, Johnson AL et al. Recovery from chronic fatigue syndrome after treatments given in the PACE trial. *Psychological Medicine*2013;43(10):2227-2235.

9. ME Association. ‘ME/CFS Illness Management Survey Results: No decisions about me without me’. Patient Survey, May 2015.<http://www.meassociation.org.uk/wp-content/uploads/2015-ME-Association-Illness-Management-Report-No-decisions-about-me-without-me-30.05.15.pdf>

10. Twisk F, Geraghty K. Deviant Cellular and Physiological Responses to Exercise in Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. *Jacobs Journal of Physiology* 2015;1(2):007, 2015.

11. Hooper M. Gibson Inquiry – Day 1 April 18th 2006 - Group Testimonies, Comments by Professor Malcolm Hooper 21st April, 2006.<http://www.meactionuk.org.uk/Hooper_on_Gibson_Inquiry_Day_One.htm>.

12. Jason LA, Torres-Harding S, Brown M et al. Predictors of change following participation in non-pharmacologic interventions for CFS. *Tropical Medicine and Health* 2008;36(1):23-32. DOI: 10.2149/tmh.36.23.

13. Price JR, Mitchel E, Tidy E, Hunot V. Cognitive behaviour therapy for chronic fatigue syndrome in adults. *Cochrane Database of Systematic Reviews* 2008, Issue 3.

14. Sharpe M, Goldsmith KA, Johnson AL, Chalder T, Walker J, White PD. Rehabilitative treatments for chronic fatigue syndrome: long-term follow-up from the PACE trial. *The Lancet Psychiatry*2015a;2(12):1067-1074.

15. Juenger J, Schellberg D, Kraemer S, Haunstetter A, Zugck C, Herzog W, Haass M. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables.*Heart* 2002;87(3):235-241. <http://dx.doi.org/10.1136/heart.87.3.235>

16. Wearden A, Dowrick C, Chew-Graham C et al. Nurse led, home based self help treatment for patients in primary care with chronic fatigue syndrome: randomised controlled trial. *British Medical Journal* 2010;340:c1777.

16. Komaroff AL. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Real Illness. *Annals of Internal Medicine* 2015;162:871-872.

17. Action for ME. *‘Severely neglected’*. Patient Survey, 2001.

18. 25% ME Group. Stakeholder Response to NICE CG53 Three Yearly Review, Nov, 2010. <http://www.angliameaction.org.uk/docs/25megroup-nice-cg53-response-nov2010.pdf>(accessed January 2016).

19. Roberts E, Wessely S, Chalder T et al. Mortality of people with chronic fatigue syndrome: a retrospective cohort study in England and Wales from the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Clinical Record Interactive Search (CRIS) Register, Lancet, (published online Feb 9.), 2016.

20. Crowhurst G. Supporting people with severe myalgic encephalomyelitis.*Nursing Standard* 2005;19(21):38-43.

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