

Fatigue Explained by ME Research UK (MERUK)

The real experience of 'fatigue'

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ME/CFS is more than simple fatigue

Fatigue is a disabling consequence of a wide range of chronic diseases, including cancer and multiple sclerosis. It was one also of the symptoms associated with past outbreaks of myalgic encephalomyelitis (ME); in his famous 1959 review of outbreaks ([read more; pdf](#)), Sir Donald Acheson described, "...a period of convalescence prolonged by fatigue, aches and pains, depression and lack of concentration." And today, fatigue is one of the constellation of symptoms that define 'Chronic Fatigue Syndrome', the diagnostic entity which superseded ME in the minds of healthcare professionals from the 1990s onwards.

We all know, however, that the bald word 'fatigue' doesn't begin to describe the experiences of ME/CFS patients. Many of them point out that their major problem is not the fatigue *per se* (which is shared with perhaps 1-4% of the population), but the conjunction of post-exercise severe fatigue, malaise, pain and other symptoms. We also know that the 'fatigue' in ME/CFS patients is more severe than in many other diseases.

This was shown in an ME Research UK-funded study ([see report](#)) by Prof. David Jones and colleagues at Newcastle University who examined data from 600 people across 5 chronically ill disease groups; non-alcoholic fatty liver disease, vasovagal syncope, primary sclerosing cholangitis, primary biliary cirrhosis, and ME/CFS. The most startling finding was that fatigue severity was far higher in the ME/CFS patients than any of the other patient groups (total Fatigue Impact Scale score 102, compared with the primary biliary cirrhosis group which was next highest at 41), and that it impacted on other aspects of life, such as cognitive and social functioning.

Clearly, there is something very different about the experience of 'fatigue' in ME/CFS, and serious research work is needed to tease out the elements that distinguish it from fatigue in other diseases.

There have been some academic studies examining the types of fatigue in ME/CFS, such as [the 2009 study](#) which used factor analysis to classify types, yet studies focussing on what fatigue *means* to patients and how it impacts on their *lived* experiences remain as rare as hens' teeth. That's why a new study published in the journal *BMJ Nursing* ([read more](#)) is particularly valuable - it lets the patients have their say, and classifies their experiences in a comprehensive way.

The researchers, Eva Stormorken [photo online in article] and Prof Leonard Jason's team at DePaul University in Chicago, decided to explore the in-depth the experiences of fatigue among Norwegians diagnosed with a 'post-infectious fatigue syndrome' who had been chronically ill for 4 years following infection with the parasite *Giardia lamblia*.

These patients are closely similar to people diagnosed with ME/CFS in the UK and USA, many of whom become ill after an infection and who remain chronically ill for several years or more. In total, 26 adults aged 26 - 59 years old were recruited from a database of patients seen at the Department of Neurology, Haukeland University Hospital, Bergen. Each had an in-depth, face-to-face interview using an open-ended interview approach that allowed for the maximum amount of information to be garnered. Content analysis of the interviews enabled a number of fascinating 'themes' to be identified.

A major theme was the **extensive and pervading** nature of the ME/CFS patients' fatigue - a whole-body experience described as "all-pervasive", "feeling old" and being "out of control" that greatly reduces the person's ability to function personally or professionally. These descriptions are certainly very different from the notion of 'fatigue' as vague tiredness held by the general public.

Digging deeper, the particular elements of fatigue that the patients described included not only **physical fatigue**, including muscle weakness, but also a range of less well-recognised aspects, such as **emotional fatigue** (impatience, lowered stress intolerance, etc.); **'wired but tired'**, where mind is working overtime even though the body is not ("the machinery can't relax"); cognitive fatigue, or **brain fog**, characterised by difficulties finding words, concentrating or remembering ("brain not in function"); and **weird body experiences**, such as hypersensitivity to noise or light, vision and hearing problems, temperature regulation difficulties, pins and needles ("The body becomes weird inside... shivering too...").

Importantly, the participants also reported **fatigue on awakening**, characterised by poor sleep, a prolonged awakening process, and feeling drowsy and unrefreshed - waking up completely could take several hours ("I've just been lying in hibernation... my body needs time to wake up..."). As the authors point out, fatigue on awakening is rarely recognised by healthcare professionals, but should be.

Illness, malaise and flare-up of symptoms after exertion, even mild exertion, was a prominent feature of these ME/CFS patients' reports, with relapses due to overexertion lasting for hours, days, and in the most serious cases, for months. Patients also reported a **lack of endurance and stamina** ("being completely empty and tired faster"); being **unable to multitask**, or even do several things in the same day; and taking much **longer to recover** from over-exertion than normal. One of the most unusual findings was **'beyond time' feelings**, described as a state of mind when time passes without full consciousness and no awareness of what is going on; some patients described it as "lethargy", "being a zombie" or "the mind in a shutdown mode". Indeed, several participants reported substantial gaps in their memory of the preceding 4 years.

And some patients highlighted their inability to instruct the body to perform on demand ("It's not my willpower that governs... the symptoms govern daily life").

The factors triggering fatigue and the flare-up of symptoms in the patients were various. They could be physical, such as walking or standing up; cognitive (reading or using a computer); emotional (watching films with emotional content); neurological (lights, or busy public spaces). Social situations could also trigger flare-ups, and some patients reported financial worries adding to the strain ("Economic problems worsened my fatigue").

The key point, as the authors point out, is that *"The term fatigue does not capture the participants' experiences, which are accompanied by a considerable symptom burden that contributes to the illness experience and the severe disability."*

In fact, the patients' 'fatigue' was multifaceted, multidimensional, and far removed from the everyday 'tiredness' experienced by healthy people. This central fact needs to be brought home to the public in general, and medical staff and other healthcare professionals in particular, if the real, lived experiences of people with ME/CFS are ever to be understood and taken seriously. For that reason, Eva Stormorken and Prof Leonard Jason's report is an important contribution to the literature on this illness and should be widely read by nurses and clinicians - as well as patients' families and friends!

Further reading

Fatigue in adults with post-infectious fatigue syndrome: a qualitative content analysis. Stormorken E, et al. BMC Nurs, 2015 Nov 28; 14: 64. [Read more](#). Perceived fatigue in different disease groups. Jones DE, et al. Quarterly Journal of Medicine, 2009 Sep; 102(9): 617-24. An ME Research UK-funded study. [Read more](#).

The clinical syndrome variously called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia. Acheson ED. Am J Med, 1959; 26: 569-95. [Read more](#) (pdf).

Biological mechanisms of chronic fatigue. Norheim KB, et al. Rheumatology (Oxford), 2011 Jun; 50(6): 1009-18. [Read more](#).