

Severe Myalgic Encephalomyelitis
Understanding and Remembrance Day
(8th August)



Myalgic Encephalomyelitis (M.E.) is one of the most disabling diseases there is. The level of disability can exceed that in Polio, MS, advanced HIV, and other serious illnesses, including the effects of chemotherapy.

'An M.E. patient feels effectively the same every day as an AIDS patient feels two weeks before death.' Mark Loveless, Infectious Disease Specialist.

'I am a ghost in the land of the living – forgotten, ignored and drifting on the edges of life, whispering my message in the ears of the lucky ones who can participate in life...I have Myalgic Encephalomyelitis...I call it paralysis, muscle and cardiac failure, brain injury, a living plague that kills only slowly, but does kill...'

Aylwin (Jennifer) Catchpole, M.E. patient, died in August 2010

What causes Myalgic Encephalomyelitis?

Myalgic Encephalomyelitis is an acquired neurological illness often triggered by a viral infection. The disease often has a sudden onset - people felt well beforehand and then one day they become very ill. Often, people can tell you the exact date when Myalgic Encephalomyelitis struck.

Incredibly, to date, the UK Government have put no funding into biomedical research for this serious, long-term, disabling disease. There is at present no effective treatment for M.E., beyond limited symptomatic relief.

Myalgic encephalomyelitis has been totally buried in a sea of fatigue patients and precious funding has been wrongly channelled into the study of fatigue, with M.E. being misrepresented under the umbrella term CFS, which has nothing to do with this neurological disease that affects multiple systems of the body.

How does 'Severe' Myalgic Encephalomyelitis differ from milder forms?

Those with severe Myalgic Encephalomyelitis are either bedbound and/or virtually or completely housebound. They require unique care due to the tendency for the illness to be exacerbated by everyday stimuli such as light, noise and movement. They are often too ill to use a wheelchair, or can only do so to a very limited degree. Many need to spend their time lying flat in silence and darkness to avoid deterioration. Some are tube-fed, incontinent, unable to communicate, allergic to medications, and unable to move.

Those with very severe Myalgic Encephalomyelitis experience profound levels of suffering and extreme symptoms, which can be life-threatening. Life may be reduced to basic survival, struggling moment by moment to breathe, eat, and drink, while enduring extreme pain.

How many people have severe Myalgic Encephalomyelitis?

Due to the lack of research, we simply do not know. In the UK, there are thought to be approximately 250,000 people with M.E., about three times as many as have Multiple Sclerosis. It is estimated that about 25% of people with the disease are severely affected (virtually or completely house-bound or bed-bound).

How do people become so very ill?

Some people with Myalgic Encephalomyelitis are severely affected from the first day of the illness. In other cases a 'milder' form of Myalgic Encephalomyelitis may worsen and become severe. It should be stressed though, that even so-called 'mild' M.E. involves a reduction in functioning of 50% or more – so it is by no means a mild illness. In some people the severity increases over time. The progress of the disease is unpredictable, and few recover fully.

Isn't the main symptom fatigue?

No. This is an uneducated myth. Fatigue is a common feature experienced in both good health and illness at some time or other, so using words like *fatigue*, *malaise*, *fatiguability* are simply insulting and trivialise this serious neurological disease. M.E. is not caused by deconditioning and wrong thoughts, as it is currently being misrepresented, leading to fatigue. It is a neurological disease which causes physical harm to the brain, spinal cord and multiple systems of the body.

'Myalgic Encephalomyelitis is a systemic disease with many systemic features but it is characterised primarily by CNS dysfunction and not by fatigue.'

Dr Byron Hyde, The Clinical and Scientific Basis of M.E.

What are the symptoms of Severe Myalgic Encephalomyelitis?

It is usual for people with severe M.E. to have between 50 and 100 separate symptoms. The impact of these combined is overwhelming and hard to communicate. Possible symptoms include

<p>Post-exertional flare up of symptoms (universal)</p> <p>Pain can be severe/intractable, may include headaches or migraines, muscle pain (myalgia – again universal), widespread body pain, persistent sore throat</p> <p>Cognitive dysfunction (e.g. difficulties with concentration and reading, muddling words, memory loss, dyscalculia)</p> <p>Gastrointestinal problems (e.g. nausea, vomiting, food intolerances and allergies)</p> <p>Inability to be upright due to orthostatic intolerance</p> <p>Disabling sensitivities to stimuli (e.g. to noise, light, vibrations, odour, movement)</p>	<p>Seizures</p> <p>Balance problems and dizziness</p> <p>Reactions to chemicals and medications</p> <p>Paralysis</p> <p>Paresis</p> <p>Breathing difficulties</p> <p>Impaired consciousness, blackouts and coma-like states</p> <p>Incontinence</p> <p>Tremors and spasms</p> <p>Visual disturbances</p> <p>Cardiac dysfunction</p> <p>Inability to chew or swallow</p> <p>Difficulty regulating body temperature</p> <p>Stroke-like experiences</p>
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... and the list goes on. The disease can cause dysfunction in all the major systems - neurological, immune, endocrine, cardiovascular, musculoskeletal, gastrointestinal, respiratory, and genito-urinary, which is why people with Myalgic Encephalomyelitis have so many symptoms.

The characteristic distinguishing feature of M.E. is the way in which symptoms are exacerbated by activity and sensory stimuli. Patients experience flare ups following physical, cognitive, sensory or orthostatic activity beyond their limitations (difficulty in remaining upright, whether sitting or standing). The flare up may be immediate, or delayed, so it may not be visible to an outside observer that a patient is exceeding their capabilities. The severity of the illness is defined by how much activity the person can manage without causing a 'crash' in their health.

In the very severely affected, exacerbations can be triggered by such trivial things as conversation, teeth cleaning, being moved to prevent pressure sores, sitting up in bed for a few minutes, the noise of a plane, or the brightness of the sun shining through curtains.

People whose Myalgic Encephalomyelitis is less extreme, can manage some activities, but are likely to need complete rest before and after activities, and to avoid overexertion, in order to maintain stability in their health.

Who gets Myalgic Encephalomyelitis?

Anyone can get this illness. It affects people of all ages including young children, people of all cultures and nationalities, regardless of how much money they have or whether they are happy or sad. It may have a genetic component, as it seems to be more common in close relatives, and it occasionally occurs in geographical clusters.

Why have an awareness day just for the severely affected?

The severity of this illness often makes it impossible for people to have contact with loved ones, doctors, or the outside world. This is a group of people who are generally invisible. In helping to make visible the stories of people living with severe M.E., and of those who have died as a result of the illness, you can help end years of misrepresentation about M.E. and increase understanding. The seriousness of the disease is often underestimated. This causes much suffering to those with M.E., who have a double battle - with the disease itself, and to get their illness taken seriously.

What's the significance of 8th August?

This is the birth date of Sophia Mirza. Sophia was bed-bound with severe Myalgic Encephalomyelitis and was a victim of medical abuse. Her doctors did not believe that M.E. was a physical disease and so she was forcibly taken from her bed/home by social workers, police officers and doctors, and kept in a psychiatric facility where she received inappropriate treatment and care. Sophia subsequently died of M.E. at the age of 32. Her post-mortem revealed widespread inflammation in the spinal cord (ganglionitis). You can read Sophia's story here www.sophiaandme.org.uk

Thank you for reading this pamphlet. The children and adults with Severe Myalgic Encephalomyelitis appreciate your interest.

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