

Symptoms

The Canadian Consensus Criteria defines ME/CFS as:

Fatigue

A significant degree of new, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity.

Post-exertional malaise

A worsening of symptoms after physical or mental exertion, including a loss of physical and mental stamina, rapid muscular and cognitive fatigability, and/or pain. The recovery period is slow — usually 24 hours or longer.

Sleep dysfunction

Unrefreshing sleep or rhythm disturbances such as reversed or chaotic sleep rhythms.

Pain

In the muscles, and/or joints, often widespread and migratory. Often there are significant headaches of new type, pattern or severity.

...in addition to

The person will also have two or more neurological/cognitive manifestations, and one or more symptoms from two of the categories of autonomic, neuroendocrine, and immune.

The illness should persist for at least six months (three months in children), although diagnosis may be possible earlier. It usually has a distinct onset, although it may be gradual.



Fighting for Equality

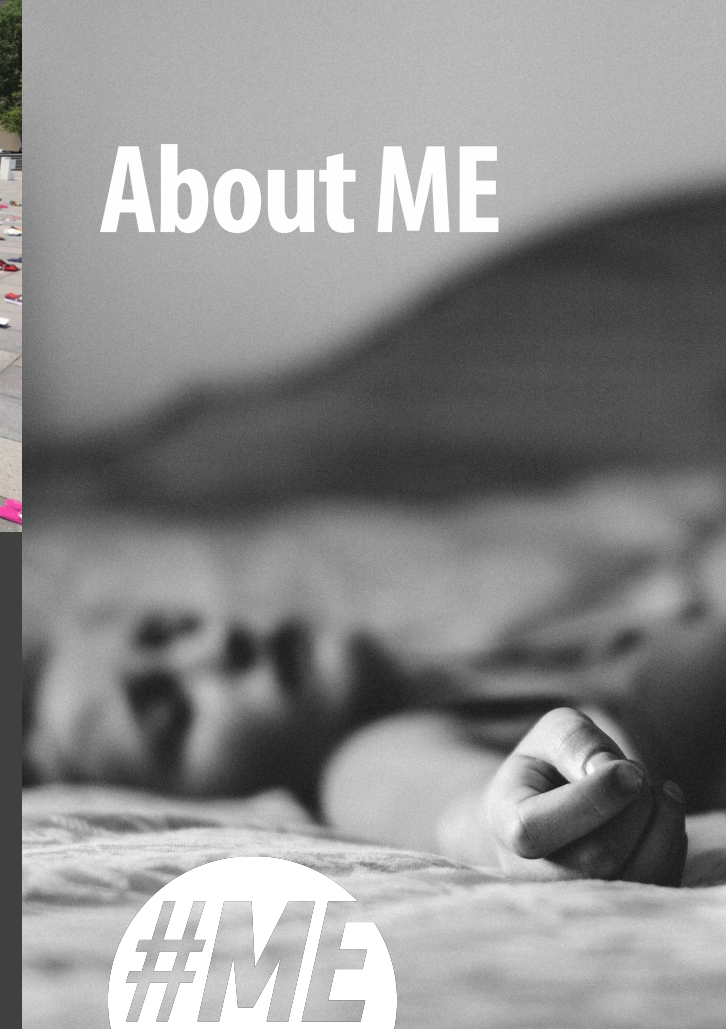
#MEAction is a member-driven 501(c)3 non-profit organization and international network of patients fighting for health equality for ME.

In 2016, #MEAction spearheaded the #MillionsMissing movement. People with ME and supporters took to the streets in dozens of cities globally to demand health equality from their governments. The empty shoes represent the millions of people missing from their lives from this neglected disease.

Learn more

MEAction.net

About ME



People with Myalgic Encephalomyelitis must learn to navigate a new world of illness, often without the guidance of doctors. #MEAction is empowering people to form a global community and fight for change.

Myalgic Encephalomyelitis (ME), commonly known as Chronic Fatigue Syndrome (CFS) or ME/CFS, is a devastating multi-system disease that causes dysfunction of the neurological, immune, endocrine and energy metabolism systems.

What does ME look like?

ME is a spectrum disease. All people with ME experience a substantial loss of physical or cognitive functioning, but there is a wide spectrum of severity. On average, ME patients score more poorly on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure, and various cancers.

ME leaves 75 percent of those affected unable to work and 25 percent homebound or bedbound.

At the "mild" end of the spectrum, patients may lose up to 50 percent of their previous function. Some are able to continue to study or work with accommodations, and by resting while not working. More moderate patients are forced to abandon careers they loved.

At the most severe end of the spectrum, patients may live the rest of their lives in darkened rooms, unable to tolerate light, sound, or human touch. Only 4-8 percent fully recover.

The medical situation

People with ME often spend years visiting countless doctors who cannot diagnose them. ME is taught in just 6 percent of American medical schools. While researchers have documented multiple abnormalities in patients, there is no readily available diagnostic test.

Currently, there are no FDA approved treatments for ME. So, patients are often left to experiment with medications and therapies that can treat individual symptoms. People with ME have had some success from various off-label treatments.

Hope for the future

Scientists across the US, the UK, Norway, Germany, Japan and Australia continue to publish both findings on biological abnormalities, and progress towards finding biomarkers. Scientific studies have shown metabolic dysfunction affecting cellular metabolism in people with ME, as well as neurological inflammation, systemic inflammation, immunodeficiency and an altered microbiome.

Statistics on ME



It is estimated that at least **1 million** Americans and **15 to 30 million** people worldwide live with ME.



ME affects men, women and children, and **75 percent** of people with ME are women.



ME costs the U.S. economy **\$17 to \$24 billion** a year in lost productivity.



There are no diagnostic tests making it extremely difficult to receive a diagnosis. In 2015, the Institute of Medicine proposed a new diagnostic criteria to better equip doctors.



Although there are no FDA approved treatments for ME, the annual federal research budget is a mere **\$13 million** per year. In comparison, MS receives **\$115 million** per year and is half as common.