

# 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.



## Fight for your health

### Take action on our platform:

Promote your petition, fundraiser or event.  
Join our Congressional team. Read case studies to see what has been done before.  
Submit an article or opinion piece about ME.

Join us at  
[MEAction.net](http://MEAction.net)

**"I have ME.  
What's next?"**



Living with Myalgic Encephalomyelitis can be a lonely and difficult experience. #MEAction was formed to be your support community and knowledge source.

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.

## Diagnose & adapt

There is no single laboratory test that can diagnose ME. A diagnosis is also often made by excluding other conditions that cause similar symptoms, and by using the Canadian Consensus Criteria (ICC) which is listed in this leaflet.

If you suspect you have ME, try to adapt your life to your "new normal" of reduced energy levels. This may involve learning about pacing, asking for help from friends, family or disability organizations, or going on sick leave. While not easy, this offers you the best chance of slowing or halting progression, and even regaining some function.

## Find a doctor

Most doctors have not been educated on ME. In the U.S., the disease is taught in just 6 percent of medical schools. People with ME have mostly reported negative experiences with their doctors who either fail to diagnose them, or misdiagnose them as depressed, or stressed-out.

#MEAction has crowdsourced a global directory of ME specialists. See [meaction.net](http://meaction.net).

## Learn from others

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. Scientific research continues to reveal the biological abnormalities in people with ME. Read the latest on [meaction.net](http://meaction.net).

## Demand change

Governments around the world have failed to invest in the research into ME, leaving those afflicted without diagnosis or treatments. In the U.S., the annual federal research budget is a mere \$13 million per year for ME. Based on the number of people affected and the severity of the disease, government funding for ME should be around \$250 million.

#MillionsMissing began in 2016 as a movement to achieve research equality for ME. The ME community took to the streets in cities globally to demand investments from their governments into research and medical education.



While it may be difficult to advocate for ourselves in the physical world, in the virtual world we can be **AN UNSTOPPABLE FORCE**

## Join the community

#MEAction is a member-driven 501(c)3 non-profit organization and international network of patients fighting for health equality for ME. We provide the platform and tools to help you connect with others, and scale your advocacy.

**We focus on 3 main areas:**

- 1** Support and connect people with ME and their caretakers.
- 2** Educate and advocate with and for people with ME.
- 3** Organize for long-term research, policy, and cultural change around ME.

Visit [meaction.net](http://meaction.net) to find resources and to connect with the #MEAction community.