

Myalgic Encephalomyelitis (ME)

FACTSHEET

1. What is ME?

Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is a disabling, chronic and complex disease.

People with ME are not able to function the same way they did before they became ill. ME changes people's ability to do daily tasks, like taking a shower or preparing a meal. It often makes it hard to keep a job, go to school, and take part in family and social life. At least one in four people with ME are bed- or house-bound for long periods during their illness.

Researchers have not yet found what causes ME, and there are no specific laboratory tests to diagnose ME directly. Therefore, doctors need to consider the diagnosis of ME based on in-depth evaluation of a person's symptoms and medical history. It is also important that doctors diagnose and treat any other conditions that can cause similar symptoms.

2. How common is ME?

Between 17 and 30 million people are estimated to have ME across the world, or approximately 1 in every 250 people. However, over 84% of people with ME are thought to be undiagnosed.

3. Symptoms

ME can get worse after **any** activity. This hallmark symptom is known as **post-exertional malaise (PEM)**. The ability of people with ME to do their usual activities is greatly lowered. At times, ME may confine them to bed. People with ME have overwhelming fatigue that is not improved by rest. They may not look ill. In addition to PEM, symptoms include:

- Fatigue - feeling very ill and weak
- Cognitive dysfunction
- Orthostatic intolerance (difficulty standing upright)
- Unrefreshing sleep
- Bloating and and nausea
- Flu-like feeling
- Pain
- Sensitivity to noise and light
- And more...

Post-exertional malaise

The worsening of symptoms after physical, mental, or emotional exertion that would not have caused a problem before the illness, which is the hallmark symptom of ME. For some patients, sensory overload (light and sound) can induce PEM. PEM intensifies the severity of symptoms and may last days, weeks, or permanently. The symptoms typically begin to worsen 12 to 48 hours after the activity or exposure.



When pushing harder can make you sicker...



4. Who is affected?

Anyone can get ME. The illness affects children, adolescents, and adults of all ages. Among adults, women are affected more often than men.

The majority of people with ME report an infection at the start of their symptoms, that they never fully recover from.

5. Support

People with ME can be supported by family, peers, employers, health care professionals and the community. There is no universally effective treatment or cure, but healthcare professionals can provide advice and medicines to help with symptom management.

All people with ME should be advised not to use more energy than they perceive they have – they should manage their daily activity and not 'push through' their symptoms.

6. Impact

For 95% of people with ME, it is a chronic, life-long illness. Just 5% make a full recovery. Daily activities become challenging, and even small amounts of exertion can lead to an increase in other symptoms. People with ME have a lower average quality of life than people with diabetes, multiple sclerosis, stroke or various cancers.

Initial research suggests roughly 75% of people with ME are unable to work, and many rely on care.

7. What is the link with long COVID?

The number of people with ME is rising dramatically due to COVID-19. Roughly half of those with long COVID meet the criteria for an ME diagnosis.

This means tens of millions more people experiencing post-exertional malaise and debilitating ill-health.



8. Find out more

World ME Alliance information about ME: worldmealliance.org/what-is-me

The World ME Alliance is made up of national ME organisations from across the world. Find your nearest organisation at: worldmealliance.org/our-members