

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a long name for a complex disease with many disabling symptoms. ME/CFS impacts many parts of the body and makes people very sick.

Myalgic encephalomyelitis (ME) is a medical name, and when it is broken down, it means:

- Myalgic means muscle pain
 - Encephalo refers to the brain
 - Mye means spinal cord
 - -itis means inflammation.
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ME/CFS is a disease that affects many parts of the body:

- Brain
- Muscles
- Stomach and digestion
- Immune system (the part that fights sickness)
- Blood circulation.

It can start suddenly or slowly. Some people can still work or go to school. Some are too sick to get out of bed¹.

How is it like long COVID?

About half of the people who stay sick after COVID have symptoms like people with ME/CFS^{2,3}.

Common symptoms of ME/CFS

- Post-exertional malaise (PEM) — feeling much worse after doing even tiny amounts of activity
- Trouble sleeping or not feeling rested after sleep
- Pain in muscles, joints, or the head
- Difficulty thinking, focusing, or remembering
- Trouble with noise or bright light
- Feeling dizzy or worse when sitting or standing
- Feeling sick or having stomach pain⁴.

Who can get ME/CFS?

Anyone — young or old, but ME/CFS can't be caught from someone else ⁴.

What can cause ME/CFS?

Doctors do not know. It can happen after:

- A virus or infection (like the flu or glandular fever)
- Contact with harmful chemicals
- A significant injury or accident
- An operation (surgery)
- Stress or emotional trauma ⁴.

How do doctors diagnose ME/CFS?

There is no single test.

Doctors check people carefully to make sure there is no other reason for their symptoms.

People must have problems with the following to be diagnosed with ME/CFS.

- Waking up tired
- Feeling very tired all the time for more than 6 months
- Post-exertional malaise (PEM) - feeling much worse after doing even tiny amounts of activity.

Either:

- Problems thinking or remembering things
- or
- Feeling sicker when standing or sitting.

How long does it last?

A small number of people get better, but recovery can be slow. Some improve, others stay the same and about 20% get worse over time ^{5,6}.

How is it managed?

There are things you can learn and do to help manage your symptoms:

- Learn about PEM (add link)
- Learn how to look after your energy (add link)
- Rest.

There are also things your doctor can help with:

- Symptoms management⁷.

Reference

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