CONDITION

Myalgic encephalomyelitis/chronic fatigue syndrome

ME/CFS is a long-term condition that causes disabling fatigue and worsening symptoms after physical or mental activity.

WHAT IT IS
Long-term multisystem condition with post-exertional symptom worsening

BODY SYSTEM
Nervous, immune, and circulatory systems

MAIN SYMPTOMS
Post-exertional malaise, disabling fatigue, unrefreshing sleep, thinking problems

WHAT CAUSES IT
Unknown; often begins after infection

HOW IT IS DIAGNOSED
Clinical criteria and tests excluding other causes

MAIN TREATMENT
Energy management and treatment of individual symptoms

CAN IT BE CURED?
No, no established cure currently

IS IT AN EMERGENCY?
Sometimes, chest pain or severe breathing difficulty

LONG-TERM OUTLOOK
Some improve, but many have persistent limitations

Overview

Myalgic encephalomyelitis/chronic fatigue syndrome, usually shortened to ME/CFS, is a complex long-term condition. It affects several body systems and can limit physical activity, thinking, sleep, work, education, and social life.

ME/CFS is more than feeling tired. Its defining feature is post-exertional malaise , often called PEM. This is a worsening of symptoms after physical, mental, emotional, or social activity that would not previously have caused a problem. The worsening may begin hours later, often the next day, and can last days or longer.

Rest does not fully relieve the fatigue. Sleep is often unrefreshing, meaning you may wake

feeling as tired as when you went to bed.

ME/CFS ranges from mild to very severe. Some people can continue working or studying with adjustments. Others are mostly housebound or need help with everyday care. People with very severe ME/CFS may be confined to bed and highly sensitive to light, sound, touch, or movement.

The condition is real, even when routine test results are normal. There is currently no single test that confirms it and no established cure, but careful management can reduce symptom flare-ups and address specific problems.

Symptoms

Symptoms can change from day to day. They may also worsen after an infection, stressful event, disrupted sleep, or more activity than your body can currently tolerate.

The main features are:

Problems caused by standing or sitting upright are called orthostatic intolerance . Symptoms often improve when you lie down. One form is postural orthostatic tachycardia syndrome, or POTS, in which the heart rate rises unusually when standing.

Other possible symptoms include muscle or joint pain, headaches, sore throat, tender glands, nausea, bowel problems, temperature sensitivity, and flu-like feelings. Some people become unusually sensitive to light, noise, smells, touch, or medicines.

PEM is not simply ordinary tiredness after activity. A person may manage an appointment or outing but then have a marked symptom flare later. During a flare, basic tasks such as showering, talking, reading, or preparing food may become difficult.

- A substantial fall in your previous ability to work, study, exercise, socialise, or manage daily tasks
- Fatigue that is not explained by ongoing exertion and is not substantially relieved by rest
- Post-exertional malaise after physical, mental, emotional, or social activity
- Sleep that does not leave you refreshed
- Problems with memory, concentration, word-finding, or processing information
- Dizziness, weakness, palpitations, or feeling faint when upright

Causes and risk factors

The cause of ME/CFS is not known. Research has found changes involving immune function, energy use, the nervous system, and regulation of heart rate and blood pressure. It is not yet clear which changes cause the illness and which are effects of it.

ME/CFS often starts after an infection. Reported triggers include glandular fever and other viral or bacterial illnesses. Some people develop an illness after COVID-19 that meets ME/CFS criteria, although long COVID and ME/CFS are not identical in every person.

Other people develop symptoms gradually or cannot identify a trigger.

ME/CFS can occur at any age and in people of any background. It is diagnosed more often in women, but it also affects men and children. More than one family member can be affected, yet no simple pattern of inheritance has been established.

The condition is not caused by laziness, lack of motivation, or simply being unfit. Anxiety and depression can occur alongside ME/CFS, as they can with other long-term conditions, but they do not explain its full pattern of symptoms.

Diagnosis

There is no blood test, scan, or other test that confirms ME/CFS. Diagnosis is based on your symptoms, how long they have lasted, their effect on daily life, and whether another condition better explains them.

Different clinical criteria use somewhat different time periods. Current guidance may allow diagnosis after several months of persistent symptoms, while some criteria require six months. Children may be assessed differently.

An assessment usually includes a detailed history and physical examination. You may be asked about activity before and after becoming ill, sleep, pain, thinking problems, upright symptoms, medicines, infections, and mental health.

Blood and urine tests are commonly used to look for other causes. Depending on your symptoms, these may assess blood counts, inflammation, thyroid function, blood sugar, and liver or kidney function. Further tests might be appropriate when there are signs of a sleep disorder, heart condition, neurological illness, autoimmune condition, or another specific problem.

Normal routine tests do not mean that symptoms are imagined. They mean that common alternative explanations have not been found.

Conditions that can resemble or occur alongside ME/CFS include anaemia, thyroid disorders, sleep apnoea, diabetes, coeliac disease, inflammatory conditions, medication effects,

depression, and some heart or neurological conditions. A person can have ME/CFS and another condition at the same time.

Treatment and management

There is no treatment proven to cure ME/CFS. Management focuses on reducing symptom flare-ups, treating individual symptoms, and helping you maintain as much independence and quality of life as possible.

Energy management , sometimes called pacing, is central. It involves balancing activity and rest so that physical, mental, emotional, and social demands stay within your current energy limits. Activities such as concentrating, talking, travelling, or coping with noise can use energy as well as physical movement.

A diary or activity tracker may help identify patterns, but tracking should not become an extra burden. Energy limits can change, so a plan may need adjusting during infections, relapses, or periods of improvement.

Pacing does not mean complete inactivity. Gentle movement may help comfort and joint mobility when it can be done without triggering PEM. However, exercise programmes based on fixed increases in activity should not be used as a cure. Pushing through symptoms can cause prolonged worsening. Any physical activity plan should be flexible and shaped around your response.

Treatment may also address:

Cognitive behavioural therapy, or CBT, may help some people cope with symptoms, loss, or changes in daily life. It is not a cure and should not be presented as a way to think yourself out of ME/CFS.

There is no special diet proven to cure the condition. A balanced diet is appropriate when possible. People who cannot shop, prepare food, chew, or swallow easily may need practical support and nutritional assessment.

People with severe or very severe ME/CFS may need home-based care, reduced light and noise, communication adjustments, pressure-area care, and help maintaining nutrition and hydration.

- Sleep problems, pain, headaches, nausea, and bowel symptoms
- Orthostatic intolerance, using practical measures and medical treatment when appropriate
- Mobility, washing, dressing, eating, and other daily needs

- Adjustments at school, university, or work
- Emotional effects of living with a limiting and unpredictable condition

Complications

Repeated PEM can lead to prolonged relapses and a further loss of function. If upright symptoms are severe, fainting may cause falls or injury.

Long periods of limited movement can contribute to muscle weakness, stiff joints, skin pressure injuries, and reduced tolerance of being upright. These effects may complicate ME/CFS, but they do not fully explain the condition.

Severe illness can make it difficult to eat, drink, communicate, or manage personal care. Dehydration, weight loss, or malnutrition requires medical assessment.

ME/CFS can also affect education, employment, finances, relationships, and access to healthcare. Isolation and loss of independence may contribute to anxiety, low mood, or grief. New mental health symptoms deserve support without assuming they are the cause of the physical illness.

Prevention

There is no proven way to prevent ME/CFS because its cause is not understood and it often follows an unpredictable infection.

General measures that reduce the spread of infections may lower your chance of catching particular illnesses, but they cannot guarantee that ME/CFS will be prevented. There is also no proven supplement, diet, or exercise programme that prevents it.

If you already have ME/CFS, staying within your energy limits may reduce avoidable episodes of post-exertional worsening. This is management rather than prevention of the condition itself.

Living with it and what to expect

The course of ME/CFS is different for each person. Symptoms often fluctuate over months and years. There may be periods of relative stability, partial improvement, or relapse. A relapse can follow extra activity or an infection, but sometimes there is no clear reason.

Some people improve substantially, and a smaller number may recover enough that they no

longer meet diagnostic criteria. Others remain limited for many years. Even after improvement, energy limits may remain lower than before the illness. It is not possible to predict an individual course with certainty.

Learning early signs of overexertion can help you plan. Breaking tasks into smaller parts, resting before symptoms become intense, reducing unnecessary travel, and using mobility or household aids may preserve energy for activities that matter most to you.

Work or education may be possible with reduced hours, remote access, rest breaks, flexible deadlines, or a gradual return that responds to symptoms rather than a fixed timetable. Using accommodations or mobility aids does not mean that you have stopped trying.

Routine follow-up can be used to review changes, check nutrition and sleep, assess new symptoms, and reconsider whether another condition has developed. A new symptom should not automatically be attributed to ME/CFS.

When to get medical help

Arrange a routine medical appointment if you have persistent fatigue with PEM, unrefreshing sleep, thinking problems, or upright symptoms that interfere with daily life. Assessment is important because several treatable conditions can cause similar symptoms.

Seek earlier medical advice if established symptoms change significantly, you are losing weight, you often faint, pain is not controlled, or you are struggling to eat, drink, wash, or move safely.

Get urgent or emergency help for symptoms such as:

These symptoms are not assumed to be part of ME/CFS and need prompt assessment.

- New chest pain, severe breathing difficulty, or blue or grey lips
- New one-sided weakness, facial drooping, difficulty speaking, or confusion
- Fainting with injury, or fainting during exertion
- Inability to keep fluids down, very little urine, or signs of severe dehydration
- Thoughts of suicide or an immediate risk of self-harm

Common questions

Is ME/CFS the same as being tired all the time?

No. Ordinary tiredness usually improves with sleep or rest. ME/CFS causes a substantial loss of

function, unrefreshing sleep, and delayed worsening after activity. The fatigue is only one part of the condition.

Can exercise cure ME/CFS?

No exercise programme has been shown to cure ME/CFS. Fixed programmes that increase activity regardless of symptoms can trigger PEM. Movement may still be useful for comfort or mobility when it stays within your limits and is adjusted if symptoms worsen.

Can my tests be normal when I feel this unwell?

Yes. Routine tests are often normal because there is no standard laboratory marker for ME/CFS. Testing is still important to look for other causes and conditions that can be treated.

Is ME/CFS contagious or inherited?

ME/CFS itself is not considered contagious. An infection that triggers it may have been contagious. Family clusters have been reported, but there is no established simple inheritance pattern.

Will I recover from ME/CFS?

Some people improve significantly, while others continue to have long-term limitations. Symptoms can fluctuate, and improvement may be slow or uneven. No test can reliably predict what will happen for one person.

Is ME/CFS the same as long COVID?

They overlap but are not always the same. Both can involve PEM, fatigue, thinking problems, and orthostatic intolerance. Some people with long COVID meet ME/CFS criteria, while others have a different pattern of symptoms or organ effects.

Sources

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