What is ME/CFS?

Key points

- ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is an illness that has a substantial, often severe impact on people's lives and is usually long-term.
- It affects about 1 in 250 people, including children.
- Symptoms include feeling ill and exhausted, difficulty staying standing or sitting up, pain, and problems thinking or concentrating.
- Physical or mental activity can be followed hours or days later by a long-lasting worsening of the illness. This is known as post-exertional malaise.
- ME/CFS makes it difficult or impossible to keep a job, attend school, or have a social life. Some people with the illness are housebound or bedbound.
- There is no known cause or effective treatment. Some people with ME/CFS improve over time, but others worsen. Full recovery is uncommon except in teens and children and in the early stages of the illness.

Symptoms

The key feature of ME/CFS is that the illness gets worse after physical or mental activity. People with ME/CFS have limited energy and doing too much makes their symptoms more severe. The worsening can begin hours or days later and take a long time to recover from. Rest or sleep gives little relief. This is called post-exertional malaise.

Fatigue in ME/CFS differs from ordinary tiredness or sleepiness. It is an overwhelming exhaustion that prevents people from leading normal lives. Other common symptoms include a flu-like feeling, sleep issues, gut problems, pain, and difficulties with thinking, memory, or concentration.

Many people with ME/CFS can't tolerate normal levels of sound, light, smell or touch, which can make them sicker. Most people with ME/CFS also feel increasingly unwell the longer they sit upright or stand. This is known as orthostatic intolerance. Many have to lie flat or have their feet raised for most of the day.

People with ME/CFS may not look ill, but they are often severely impaired. The illness makes it hard or impossible to keep a job, stay in education, take part in social activities or do household tasks. Some are partly or completely housebound.

The most severely ill people with ME/CFS are bedridden and need help with self-care such as bathing, toileting or dressing. Many need to be in a dark, silent room because they can’t tolerate any light or sound. Some also have problems with eating, and in rare cases need tube-feeding.

Who gets ME/CFS

About 1 in 250 people have ME/CFS at any one time. It affects children and adults, including older people, from all social and ethnic backgrounds.

Around three quarters of people diagnosed with ME/CFS are female. The illness is less common before puberty. Some families have more than one member with ME/CFS, but researchers have not yet found genes linked with the illness.

ME/CFS often follows an infection such as glandular fever (also known as ‘mono’) or COVID-19.

Diagnosis

The cause and biology of ME/CFS are not yet understood. There is no lab test that can confirm whether someone has it. Doctors diagnose it by looking at the pattern of symptoms, which must be severe enough to interfere with everyday life and have persisted for several months. They do a medical exam and lab tests to rule out other diseases that may cause symptoms similar to those of ME/CFS.

Treatment

There is currently no known cure or known effective treatment for ME/CFS. Instead, individual symptoms are treated, such as sleep problems or pain. Many people with ME/CFS find it useful to pace their activities and stay within their energy limits to avoid post-exertional malaise.

A rehabilitation approach to ME/CFS encourages people to gradually increase their activity over time, to try to help them return to normal levels of activity. One such treatment, 'graded exercise therapy', has been widely studied and not shown to help. In large surveys, many people have reported becoming much worse after it. There is no evidence that other versions, such as 'graded activity' or 'pacing up', are effective or safe. Some guidelines recommend against this approach.

Cognitive behavioural therapy, which aims to change people's behaviour and thinking patterns, is sometimes used for ME/CFS but studies have not shown this approach to be useful in improving the illness.

Likely course

ME/CFS can start suddenly or gradually. Symptoms often change in type and severity over time.

In the long term, some people improve, some stay the same, and some worsen. Full recovery is uncommon except in teens and children, and in early stages of the illness. For most others, ME/CFS is a long-term illness.

References

Symptoms

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Likely Course

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