

Chronic fatigue syndrome (ME/CFS)

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is an illness characterised by exhaustion and many other symptoms. It can strike at any age and can affect children as well as adults. Victoria alone could have at least 35,000 people who suffer from ME/CFS.

Myalgic Encephalomyelitis means pain in the muscles and inflammation in the brain and spinal cord. Onset of ME/CFS may be sudden or slow and may follow viral infections, toxic exposure, trauma or other events. There can be various levels of severity of this condition. Some people can go to work or can manage moderate levels of activity, while others are housebound or bedridden.

The course of illness is difficult to predict. Some people recover quite well over a long time. Some people remain about the same, while some suffer relapses and others get worse.

A variety of symptoms

The symptoms for which ME/CFS is best known are persistent weakness and exhaustion. The distinguishing feature of the condition is a type of exhaustion known as post-exertional malaise or 'payback'. This includes abnormal exhaustion after any form of exertion and a worsening of other symptoms. The response may be delayed, perhaps beginning after 24 hours.

It can take an unusually long time to recover from this type of exhaustion. Activities that were once taken for granted now take an enormous toll on a person's health. For example, your normal walk, which caused no fatigue before, is followed by unusual tiredness that takes longer than usual to go away.

Other symptoms include:

- Cognitive (thinking and memory-related) difficulties and other neurological problems
- Disrupted sleep
- Pain
- A drop in blood pressure upon standing (orthostatic hypotension)
- Increased heart rate upon standing (orthostatic tachycardia)
- Palpitations
- Shortness of breath with exertion
- Muscle twitching and tingling
- Allergies and/or sensitivities to light, odours, touch, sound, foods, chemicals and medications
- Nausea
- Gastrointestinal and urinary problems
- Sore throat, tender lymph nodes and a flu-like feeling
- Marked weight change – extreme loss or gain
- Inability to cope with temperature changes.

Symptoms may vary even over a short time.

The cause is unknown

A single cause for ME/CFS and its ongoing effects has not been found, but research indicates problems in several areas that may be related to this condition:

- Immune, neurological and hormonal responses
- Viral or other infections
- Blood pressure, circulatory and cardiac abnormalities
- Digestive tract disturbances
- Genetic factors
- Biochemical abnormalities.

Without a known cause or cure, prevention is impossible.

No diagnostic test is available

Currently there is no single test to accurately diagnose ME/CFS. A diagnosis is made by excluding all other illnesses after six months of continuing symptoms. However, while routine medical tests may be in the normal range, additional tests may show abnormalities in many people with ME/CFS. These tests are generally done by doctors who specialise in managing this condition.

Impact of ME/CFS

Disability means that some people with ME/CFS are too ill to work, study or socialise. A person's finances may also be affected. A lack of community understanding of the difference between normal tiredness and the extreme exhaustion of ME/CFS, and the absence of a specific diagnostic test, add to the person's difficulties and often prevent a proper diagnosis.

The effects of this condition on a person's life and a lack of support and recognition for what they are experiencing can lead to depression in some people with ME/CFS.

Where to get help

- Your doctor
- ME/CFS Australia (Victoria) Tel. (03) 9791 3100 – for information, support groups, self-help courses and information on doctors and specialists who can support people with ME/CFS

Things to remember

- The most common symptom of ME/CFS is an overwhelming, persistent lack of energy and difficulty in recovering from exertion.
- The cause is unknown but research is discovering a large range of physical abnormalities in those affected.
- There is no cure but some treatments may provide relief to some people with ME/CFS.
- It is important to educate yourself, obtain support and manage the illness with the help of a doctor experienced in managing this condition.
- Listen to your body and keep activity within your limits to avoid relapse.

This page has been produced in consultation with, and approved by:

CFS/ME Victoria

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