

Chronic fatigue syndrome (ME/CFS)

Myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS), is defined by the World Health Organization as a neurological illness. The main symptom of ME/CFS is post-exertional malaise, which means having 'flu like' symptoms after exertion and not having enough energy for daily activities. It can strike at any age and can affect children as well as adults. At least 35,000 Victorians suffer from ME/CFS.

Myalgic encephalomyelitis means pain in the muscles and inflammation in the brain and spinal cord. The onset may be sudden with triggers such as viral infections, toxic exposure, anaesthetics, immunisations, gastro-enteritis or trauma. On the other hand, it may be slow onset over a period of years.

The course of ME/CFS is difficult to predict as it can have different stages. Some people recover quite well over a long time. Some people remain about the same, while some suffer relapses and others get worse.

Symptoms of chronic fatigue syndrome

The distinguishing feature of ME/CFS is a type of exhaustion known as post-exertional malaise, 'crash' or 'payback'.

Research has confirmed that people with ME/CFS have a different physiological response to activity or exercise than those who are healthy. This includes abnormal exhaustion after any form of exertion and a worsening of other symptoms. The response may be delayed, perhaps after 24 hours. Depending on the amount and type of exertion, it may result in post-exertional malaise for a few days, or serious relapses lasting weeks, months or even years.

Recovery from this type of exhaustion can take a day, weeks, months or years. Having ME/CFS means activities that were once taken for granted now take an enormous toll on a person's health. For example, your normal walk, coffee with a friend, getting your child ready for school or catching the train to work, which caused no fatigue before, is followed by unusual tiredness that takes longer than usual to go away.

Because ME/CFS is a very complex, multi-system chronic illness, many other symptoms will occur and must be present for diagnosis. These include:

- Neuro-cognitive (new difficulties in thinking, concentrating, memory loss, vision, clumsiness, muscle twitching or tingling)
- Disrupted sleep
- Pain or aches in the muscles, joints or head
- A drop in blood pressure, feeling dizzy or pale
- Palpitations, increased heart rate or shortness of breath with exertion or on standing
- Allergies or sensitivities to light, odours, touch, sound, foods, chemicals and medications
- Gastrointestinal changes such as nausea, bloating, constipation, diarrhoea
- 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 will fluctuate over short periods of time, even from hour to hour.

Cause of chronic fatigue syndrome

The biological cause is becoming better understood. Genetics appears to be a factor in many cases. Over 4,000 research articles have found that ME/CFS is associated with problems involving:

- The body's ability to produce and transport energy
- The immune, neurological and hormonal systems
- Viral or other infections
- Blood pressure, the circulatory and cardiac systems
- Digestion
- Biochemical abnormalities.

Without a known cause or cure, prevention is impossible.

Diagnosis and treatment of chronic fatigue syndrome

Currently, there is no single test to diagnose ME/CFS. A diagnosis is made by excluding all other illnesses after six months of continuing symptoms. Routine medical tests will often be in the normal range, although many additional tests will show abnormalities.

People who receive an early diagnosis and early treatment tend to do better. Having a supportive community of family, friends, school, work, employers and health workers, who understand the potential seriousness of ME/CFS, can improve recovery for people with ME/CFS. It is important to find a doctor who is not only sympathetic to ME/CFS, but can also treat it. Treatment will vary and depend on the result of the additional testing.

Impact of chronic fatigue syndrome

ME/CFS can cause differing levels of disability. Like all other chronic illnesses, ME/CFS can be anywhere from mild or moderate to severe, meaning:

- Mild – at least 50 per cent reduction in activity
- Moderate – mostly housebound
- Very severe – bed-bound and dependent upon help for all daily care.

Some people with ME/CFS are too ill to work, go to school, socialise, and manage their family or their own affairs. A person's finances will invariably be seriously affected. Community misperceptions that it is 'just being tired', 'just in their head' or 'just push through' are not helpful and can often cause a person to keep pushing beyond their limits, which will cause relapses and make the condition worse.

People with ME/CFS have an abnormal biological response to exercise or activity and this should be well understood by all involved in support and treatment.

As the organisation that supports people with this condition, ME/CFS Australia provides:

- Information, advocacy, support and research
- Community and professional education sessions
- Early intervention self-management courses (face to face and via telephone for those in rural areas or those who are housebound)
- Information on doctors who specialise in ME/CFS
- Support programs, including those for young people.

Where to get help

- Find a doctor who can understand ME/CFS
- ME/CFS Australia (Vic, Tas, NT) Tel. (03) 9791 3100

Things to remember

- The main symptoms of ME/CFS are post-exertional malaise, or 'flu-like symptoms' after activity and an overwhelming, persistent lack of energy and difficulty in recovering from exertion. It is much more than being 'fatigued'.

- The cause is very complex and not fully defined, but research has discovered many problems associated with ME/CFS.
- There is no cure. Because there are also a number of subtypes of ME/CFS, treatments will have differing effects.
- Early identification of food intolerances can be helpful.
- Undertake a self-management course as soon as possible to learn the best ways to manage ME/CFS.
- Listen to your body and keep activity within your limits to avoid relapse.

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

ME/CFS Australia (Victoria)

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