

ME/CFS IN AUSTRALIA



What is ME/CFS?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a severe, complex, chronic illness. ME/CFS affects most body systems, particularly the nervous, immune, cardiac, gastrointestinal and endocrine systems. It can devastate the health of women, men and children, leaving many unable to work, study or leave their homes for years. There is no cure and, for many, it is a lifelong condition.

ME was classified as a neurological disorder in the WHO International Classification of Diseases in 1969 (ICD 10 G93.3), in the same category as Parkinson's disease and Multiple Sclerosis.

ME/CFS is conservatively estimated to affect [0.4-1%](#) of the world's population. This means up to **240,000 Australians** may be affected.

Symptoms

The hallmark symptom of ME/CFS is 'post-exertional malaise' (PEM), extreme worsening of symptoms for days or weeks after minimal physical or mental activity, which can be delayed by 24-48 hours. Common symptoms include flu-like symptoms, widespread pain, extreme fatigue unrelieved by rest, unrefreshing sleep, sensitivity to temperature, noise and light, abnormal heart rate and blood pressure while upright, memory and concentration issues, allergies and [many others](#).

Severity of the condition ranges from mild to severe and varies, with some improving and others getting worse, over time. Even 'mild' cases involve the [loss of at least 50% of normal function](#). [Around 25%](#) of people with the illness are housebound or bedridden. Other conditions, such as fibromyalgia, and chronic infections are common with ME/CFS. Complications can occur and [life expectancy](#) may be reduced.

People with ME/CFS can be **more impaired than those with illnesses like heart disease, multiple sclerosis, or kidney failure**.

Causes of ME/CFS

The precise causes of ME/CFS are unknown. Common triggers include infections, such as influenza and Epstein-Barr; but there may be environmental triggers, such as chemical exposure or trauma.

Research has found many abnormalities including genetic, cardiac, muscle and immune system abnormalities, brain inflammation, and mitochondrial dysfunction. Researchers in Australia and elsewhere are looking for biomarkers which could be developed into diagnostic tests.

For some, the condition starts suddenly, whereas others may experience a gradual onset. There have been many [epidemic outbreaks](#) around the world, including in Australia.

Diagnosis and Treatment

ME/CFS can take years to diagnose. It is routinely misdiagnosed and is [missed as a diagnosis altogether in an estimated 84-91% of people](#). There is no single diagnostic test, no formal training in Australia for medical practitioners in ME/CFS and no medical specialty to treat it.

As there are no approved treatments, medical care consists mostly of symptom management for pain, sleep difficulties and other aspects of the illness. Daily activity pacing is necessary in order to avoid exceeding capacity, as this can cause harm, potentially worsening the illness permanently.

Challenges

ME/CFS research and medical training have been neglected for decades. The common myth (now discredited) that psychological factors play a major role in the illness, still holds back progress.

[Quality of life](#) is among the poorest of all illnesses. This, along with the stigma and disbelief, can contribute to depression, isolation and even suicide.

There are no current clinical guidelines in Australia and the Department of Health [has no specific program of support](#) for people with ME/CFS.

Australian ME/CFS research into the biomedical aspects of the condition has received [no Federal Government funding since 2005](#). Globally, [similarly disabling illnesses](#) receive 25 times the research funding that ME receives.

Government funding and appropriate recognition of the disabling nature of ME/CFS are urgently needed in order to access vital services such as home care and financial support.

For further information contact the ME/CFS organisation in your state.

#MEAction Network Australia is a group of people with ME/CFS, their carers and other healthy allies empowering each other to fight for health equality