



ME/CFS Facts

- ME/CFS affects up to an estimated 1% of people worldwide. This means up to 250,000 Australians live with the disease. ME/CFS affects people of all ages, genders and socioeconomic backgrounds.
- Approximately 75% of people with ME/CFS are women.
- Approximately 25% of people with ME/CFS are so severely impacted that they are housebound or bedbound.
- Even a mild case of ME/CFS is debilitating, resulting in 50% reduction in physical capacity compared with before they got sick.
- For most people, ME/CFS is a lifelong condition, as full recovery (return to pre-illness functioning) is rare: less than 10%.
- The key feature of ME/CFS is post-exertional malaise (PEM): pronounced “pem”, not “P.E.M.”. PEM is when all symptoms are exacerbated after physical or mental activity. It means symptoms like pain, sleep disturbance, cognitive problems, flu-like symptoms, muscle weakness all get worse. PEM can be triggered by low levels of exertion. PEM can take days or weeks to resolve. It can mean feeling like you’ve got the flu after just having a shower or a short phone call.

ME/CFS is a complex illness and myths remain about its cause and management

Here, we discuss the important facts about ME/CFS.

- Depression does not cause ME/CFS
- ME/CFS is a biological illness that involves problems with multiple body systems. It is not a psychiatric or psycho-social illness. Understandably, some people may develop depression or anxiety because they are living with a chronic illness that has caused dramatic changes to their lives.
- Depression and/or anxiety are common experiences for many people with chronic illness, but it does not mean it is the cause of the illness.
- The primary treatment for ME/CFS is pacing activity, rest and managing individual symptoms such as pain, orthostatic intolerance or sleep problems. This is different to how depression or anxiety are treated.

ME/CFS should not be referred to as chronic fatigue

People with ME/CFS are not just tired

The key symptom of ME/CFS is post-exertional malaise (PEM). PEM is where symptoms get worse after physical or mental activity. It is very disabling and causes fluctuations in a person's health: what they may be able to do one day, they might not be able to do the next. This is not just being "tired" or having fatigue all the time. Chronic fatigue is a symptom of many conditions (e.g. heart disease, cancer, multiple sclerosis) but it is not a condition in its own right. Fatigue is just one of many symptoms people with ME/CFS experience.

Unrefreshing sleep is a core feature of ME/CFS. For people with ME/CFS, their body does not "recharge" after sleep.

Calling ME/CFS "chronic fatigue" implies it is just "tiredness". It also minimises how difficult the condition is to live with. People with ME/CFS wake unrefreshed even when they have an adequate amount of sleep.

Exercise is not a cure for ME/CFS

People with ME/CFS have problems with making energy at a cellular level. They need to carefully manage how much activity they do to prevent symptoms getting worse. The old psycho-social approach was that people with ME/CFS start to fear exercise because they are deconditioned. Cognitive Behavioral Therapy (CBT) was designed to break the "fear" cycle and false "illness beliefs" and Graded Exercise Therapy (GET) was used to increase someone's ability to exercise.

All activity, from normal every-day things to exercise, must be safe. People with ME/CFS need to carefully manage how much activity they do to prevent their symptoms getting worse. For a detailed explanation of the problems with the research in this area, see [here](#).



www.emerge.org.au

1800 865 321

Health and Support Service

Speak with our friendly team during business hours, Monday to Friday. Our team can provide you with information on ME/CFS and Long COVID and support you in navigating general health and community services. We can also answer common queries related to the programs and services provided by Emerge Australia.

Visit emerge.org.au or call 1800 865 321