

Did you know?

- Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is a severe, complex acquired illness with numerous symptoms related mainly to the dysfunction of the brain, immune and endocrine systems.
- The symptoms can be made worse by physical and mental activity.
- ME/CFS can be permanently disabling in some people. Others appear to recover after about two years and some suffer frequent relapses.
- It can strike men, women and children of any age, ethnic and socio-economic group.
- The Royal Australasian College of Physicians (RACP) puts the prevalence of ME/CFS between .2% and .7% of the Australian population.
- In the year 2000, RACP conservatively estimated the disability cost to the community some \$416 million annually.
- This conservative estimate means that the direct costs of each case in that year was at least \$2,764.
- After inclusion of indirect costs (from lost productivity associated with the disorder) the annual cost of ME/CFS (in 2000) was \$13,471 to the community per case.
- ME/CFS is a major reason for absenteeism from school with up to 50% of young people with ME/CFS missing weeks and even whole terms of the school year.

What are the symptoms of ME/CFS?

- Persistent or recurring unexplained mental and physical fatigue that substantially reduces normal activity levels.
- Post-exertional malaise. Following physical and mental exertion there is a worsening of symptoms that may be delayed 24 hours or more and recovery after activity is slow.
- Dysfunctional sleep. Unrefreshing sleep, inability to fall asleep, excessive sleep, frequent awakenings, restless legs, abnormal sleep rhythms.
- Pain. Burning, aching and shooting pain in muscles and/or joints, headaches of a new type and severity, widespread tenderness.
- Cognitive problems, e.g. brain 'fog'; problems with processing and recalling information; difficulty with finding the right word, reading, writing, mathematics and short-term memory; losing track of things; forgetting names; disorientation; inability to concentrate on more than one thing; trouble with decision-making.
- Light-headedness on standing.
- Shortness of breath with exertion
- Extreme pallor
- Palpitations
- Disturbance of balance and clumsiness
- Muscle twitching
- Sensitivity to light, touch and sound
- Nausea
- Gastrointestinal and urinary problems
- Sore throat
- Tender lymph nodes
- Sweating and feverishness
- New sensitivities to foods, medications and/or chemicals
- Intolerance to temperature changes
- Cold extremities
- Marked weight-change – abnormal weight gain or loss
- A worsening of symptoms with stressors, e.g. new infection, travel, anaesthetic.

What causes ME/CFS?

The causes are not yet clearly defined. However, multiple factors may be simultaneously involved. The illness most frequently follows an acute infection, such as glandular fever, upper respiratory infections or a 'flu like' illness. In some, the illness is triggered by an exposure to chemicals, environmental pollutants or heavy metals, or follows immunisation. It can also follow a physical trauma, such as major surgery, or a serious accident. Within days or weeks of the triggering event, a progressive decline in health is experienced and numerous symptoms develop. Some people, however, cannot identify a specific initiating event and experience a gradual onset of the illness.

World-wide research is investigating the role of persistent infection, abnormalities in the immune system especially disruption to the normal defence pathway for infection, the role of environmental exposures/toxicity, nuclear imaging of blood flow in the brain, cardiac abnormalities, gut dysfunction, metabolic abnormalities and genetic factors.

How is ME/CFS diagnosed?

At present there is no specific diagnostic test. Diagnosis is based on the type and pattern of symptoms experienced and by excluding other illnesses. ME/CFS symptoms usually need to have been present for at least six months before a diagnosis is made, although a preliminary diagnosis may be possible earlier and is especially desirable in children for whom early diagnosis can be critical to recovery.



Is there a cure for ME/CFS?

There is no known cure for ME/CFS as yet. However, there is much that can be done to ease symptoms and reduce the effect of the illness. However, everyone is different and it is important to find a supportive doctor familiar with ME/CFS who will work collaboratively to explore appropriate therapies. Self-management of activity levels through pacing is widely practiced.

What's it like to have ME/CFS?

Imagine having your worst ever case of flu, add a hangover and top it off with the exhaustion of a 20 kilometre run and you have some idea of what it feels like to suffer from ME/CFS.

Most people with ME/CFS have trouble climbing stairs, standing still for any length of time and walking long distances. Many find shopping and domestic chores virtually impossible, even showering and dressing exacerbate symptoms. The most severely affected are bedridden and totally dependent on others for all care.

People with ME/CFS face many challenges. Many are too unwell to work or can only work part-time. Young people may find it hard to study and require special consideration for school attendance, assignment deadlines and exams.

Some people have well-periods followed by periods with severe symptoms. For others, the condition remains relatively stable although at any time over exertion can lead to a worsening. Most people with ME/CFS learn to schedule their activities carefully in order to achieve as much as they can without exacerbating their symptoms. However, with symptoms that may fluctuate day to day and hour to hour, it is often difficult for people to make firm plans. Socialising can be difficult or non-existent.

Relatives and friends can play a major part in supporting people with ME/CFS by showing an understanding of the condition. In each state and territory there is an ME/CFS Society that can provide information.

How long does ME/CFS last?

The RACP acknowledges that ME/CFS is a real and disabling chronic condition. Accurate predictions of recovery for individuals are not possible at this stage. It appears that early diagnosis may lessen the impact of the illness. Some make gradual progress and recover well but many do not completely regain their previous level of health. Some experience a gradual deterioration in their condition. The recovery rate for children is often better than for adults. People diagnosed with ME/CFS can generally expect to be unwell for some years.

Helpful hints for people with ME/CFS

- Find out as much as you can about ME/CFS.
- Listen to your body.
- Rest as needed. Don't push yourself.
- Pace your mental and physical activity.
- Learn from experience – you will become an expert in knowing your illness.
- Be aware of new sensitivities to drugs and therapies.
- Join an ME/CFS Society.

Donations of \$2 and over to ME/CFS Australia (Victoria) are tax deductible.

Research

The Alison Hunter Memorial Foundation (AHMF) for ME/CFS was established in 1998 to advance scientific knowledge and medical care. The Alison Hunter Memorial Foundation Medical Research Trust sponsors research into ME/CFS. Address: PO Box 6132 North Sydney NSW 2059; Website: <http://www.ahmf.org>; Ph. (02) 9922 4054; Fax: (02) 9922 4054; ABN: 27 103 523 800; CFN: 17078.

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