

# Myalgic Encephalomyelitis affects over 94,000 Australians

ME affects men, women and children of all ages, cultures and socio economic backgrounds.

## What is ME?

Myalgic Encephalomyelitis (ME) is: ... a severe, complex, acquired illness with numerous symptoms related mainly to the dysfunction of:

- the brain
- gastro-intestinal
- immune
- endocrine and cardiac systems.

**ME has been classified as a Neurological disorder in the World Health Organisation's international classification of diseases (ICD 10 G93.3) Since 1969.**

ME is also known as "Chronic Fatigue Syndrome". This is because the hallmark symptom is overwhelming post exertional malaise from minimal mental or physical exertion. ME includes a range of simultaneous symptoms that are as debilitating as the more commonly known fatigue.

## What causes ME?

There is no known cure of ME. Identifying causal factors is an ongoing challenge. Both predisposing and precipitating factors contribute to it's development including:

- Genetic predisposition
- Acute or chronic infection (including viral, bacterial and/or parasitic infections)
- A flu like illness
- Exposure to chemicals, environmental pollutants or heavy metals
- Immunisation
- Severe physical or emotional trauma

## Management & Treatment

Given the absence of curative treatments, clinical care of ME involves treating symptoms and helping with self management principles. It is important for the GP to do laboratory tests to identify abnormalities to inform symptom management. The International Consensus Primer for Medical Practitioners (2012) lists tests for this purpose.

Pacing, sleep hygiene, diet, stress management and relaxation techniques are helpful self-management strategies; the aim being relapse prevention and symptom reduction - improving the quality of life for the person with ME.

## Living with ME

Misunderstanding and lack of research, leaves people with ME isolated and vulnerable to misdiagnosis, financial insecurity and associated feelings of stigma.

Many people with ME are bounced from specialist to specialist and incur exorbitant medical expenses. It is estimated between \$5000 to \$25000 on medical expenses is not uncommon. Loss and grief is significant including: personal, social, emotional and financial. Thoughts of suicide are a common occurrence.

## What are the symptoms of ME?

### Primary symptom:

- Overwhelming post exertional malaise from minimal mental and/or physical effort.

### A range of simultaneous symptoms:

- Sleep problems
- Widespread pain and headaches
- Neurocognitive dysfunction: short term memory loss, concentration impaired, confusion, disorientation, hypersensitivity to light and sound, emotional overload
- Dizziness, inability to stand upright
- Urinary frequency, ibs, nausea
- Fluctuating body temperature
- Recurrent flu-like symptoms.

The International Consensus Primer for Medical Practitioners (2012) is the standard recommended for diagnosis and management of ME/CFS in Australia and globally. It includes diagnostic criteria, laboratory tests and management principles.

## The Effect of ME

International Studies estimate 0.4 - 1% of the population are afflicted by ME.



Over 94,000 Australians affected

25% of people affected, bedbound or housebound

Over 50% of people affected can't work or study

Over \$4Billion in lost earnings

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