

The Facts: M.E. in Australia

UP TO 240,000 AUSTRALIANS HAVE THE CHRONIC NEUROLOGICAL DISEASE, MYALGIC ENCEPHALOMYELITIS OR ME. MORE THAN A QUARTER OF PEOPLE AFFECTED ARE UNABLE TO LEAVE THEIR HOMES OR THEIR BEDS. THERE IS NO CURE BUT EARLY DIAGNOSIS AND INTERVENTION MAY LESSEN THE SEVERITY OF SYMPTOMS.



Myalgic Encephalomyelitis

Myalgic Encephalomyelitis, or ME, affects between 0.4 and 1% of the population. ME may be mild, moderate or severe. More than 25% of people affected are housebound or bedbound. People with severe ME have a quality of life similar to those with cancer and late-stage AIDS. Worsening of symptoms can be sudden and permanent. One Australian has died from ME. Life expectancy is reduced by around 25 years.

Myalgic Encephalomyelitis is classified as a neurological disease by the World Health Organisation, the same category as multiple sclerosis and Parkinson's disease. ME affects the:

- Brain
- Endocrine system
- Muscles

Diagnosis and the name 'chronic fatigue syndrome'

The name Myalgic Encephalomyelitis has been around since the 1950s. However, after an outbreak in the 1980s in the US, the criteria was widened and redefined. This new criteria was renamed Chronic Fatigue Syndrome but this criteria is broad and includes a variety of illnesses.

As more became known about ME, a more-defined set of diagnostic guidelines has been developed. The International Consensus Primer for Medical Practitioners (2012) is the standard recommended for diagnosis and management of the illness in Australia and globally. It includes diagnostic criteria, laboratory tests and management principles.

Medical research

The Australian federal government has not funded a study into chronic fatigue syndrome or Myalgic Encephalomyelitis since 2005, despite the four billion dollar effect on the economy.

In 2016, Australian researchers patented a diagnostic blood test for the illness. The test is not yet commercially available. The discovery was made at the National Centre for Neuroimmunology and Emerging Diseases at Griffith University.

In Australia, research is also being done at the Murdoch Children's Research Institute in Melbourne. Overseas, Stanford and Columbia Universities are amongst those investigating the disease.

Still, far too little research is done, considering the impact it has on so many lives.

What causes ME?

Most patients enjoyed healthy, active lifestyles prior to the onset of ME. Identifying causes is a challenge, as ME has both genetic and environmental triggers. The most common infection triggers are Ross River Fever, Q Fever, glandular fever and enteroviruses.

Is there a cure for ME?

There is no cure for ME. However, there are palliative treatments.

It is important for your GP to do laboratory tests to identify abnormalities that detect dysfunction and help 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.

More information

For a copy of the International Consensus Primer for Medical Practitioners (2012) or for more information about ME, visit MEAction.net.



#MillionsMissing