

M.E. - Myalgic Encephalomyelitis

Also known as **Chronic Fatigue Syndrome (CFS),
Tapanui Flu, and ME/CFS**

ME is a debilitating, chronic multisystem disease affecting the neurological, immune, endocrine, and energy metabolism systems. It most commonly occurs post-infection in both outbreak and sporadic patterns. It does not discriminate - affecting all ages, genders, ethnicities and socio-economic groups, leaving the majority (75%) unable to work, study or leave their homes. There is a fluctuating spectrum of symptom severity from 'mild' (just able to manage work but at the expense of other areas of life) to 'very severe' (bed-bound, tube fed, paralysed, without speech). Even 'mild' cases can involve the loss of at least 50% of normal function. Prognosis is poor with less than 5% expected to fully recover. People with ME are often more functionally impaired than those with heart failure, end stage kidney disease, or multiple sclerosis.

There are an estimated 20,000-40,000 people in New Zealand with ME

Symptoms

The hallmark symptom of ME/CFS is '**post-exertional malaise**' (PEM), which is a delayed (24-48hrs) reduction in functioning and extreme worsening of symptoms for days or weeks after minimal physical or cognitive activity.

Common symptoms include: flu-like symptoms, pain (muscle & joint), orthostatic intolerance (abnormal postural heart rate and blood pressure), muscle fatigability and weakness, neurocognitive dysfunction (memory, concentration issues), fatigue, sleep dysfunction, neurosensory sensitivity to light & noise, temperature dysregulation, weight gain/loss, gastrointestinal & genitourinary dysfunction, food & chemical sensitivities, and many others. Comorbid conditions such as POTS, MCAS, Fibromyalgia and chronic infections are also common.

Causes of ME/CFS

The causes of ME/CFS are unknown. Common triggers include viral infections such as influenza and Epstein-Barr, but there may be environmental triggers such as chemical exposure or physical trauma. Around 25% of people have a gradual onset with no obvious trigger. Most standard blood tests will show results in the normal range.

Decades of erroneous misclassification of ME as psychosomatic - despite overwhelming evidence to the contrary - continues to significantly harm people with ME. The idea that people with ME can recover by thinking more positively or pushing through their symptoms is incorrect.

Research

Research has been significantly underfunded for decades. Despite this, multiple abnormalities have been demonstrated, including neuroinflammation and mitochondrial dysfunction, as well as genetic, cardiac, muscle, and immune system abnormalities. Researchers are keenly looking for causes and biomarkers which could be developed into diagnostic tests and potential treatments.

Resources

- Visit www.m.e.awareness.nz

I am a person with ME, what do I do from here?

- View the resources at www.m.e.awareness.nz
- Learn about pacing your life and activities.
- Do not engage in programmes based on GET.
- Search for an online or 'in-person' **support group**.
- Find able-bodied allies. Look for support from friends, family, employers, WINZ.
- Provide your carers and professional supporters with the latest research and management information about ME. Or find an advocate to help you do it.

I know someone with ME - how can I help?

- See '**What you can do for ME**' Infographic
- Ask them what would make things easier for them, and what support they would like. Perhaps invite them to an event, even though they may need to cancel. Or prepare a meal, provide quiet company, or pay a bill. Manage the support you give around your own needs.
- Believe them. Learn about their experience and illness.

I am a health practitioner - how can I help?

- Educate yourself. Check out the latest research and clinical primers on our resources for health professionals page at www.m.e.awareness.nz
- Believe your patients and validate their experience.
- Consider a patient's symptoms and delayed PEM, when setting appointment times and other expectations.
- Advocate for medical education and specialists in ME/CFS, and for NZ research funding.

How can I support advocacy and research?

- Join ANZMES.org.nz, the national support charity.
- Follow [M.E.AwarenessNZ](#) on facebook and join our advocacy **group on Facebook**.
- Donate to [Prof. Warren Tate at Otago University](#)

Contact M.E. Awareness NZ

- For queries or suggestions: m.e.awareness.nz@gmail.com
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