ME/CFS

Patient Leaflet 1A

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

What is ME/CFS, Information Guide Part A

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a serious, complex and disabling illness, which causes incapacitating fatigue coupled with pain, cognitive problems, sleep dysfunction and other immune, neurological and autonomic symptoms. The person's ability to function is substantially reduced.

Estimates indicate that as many as 250,000 Australians (1%) experience this chronic condition.

The pathological loss of energy in ME/CFS is very different from the fatigue felt by healthy people following strenuous exercise or as a result of living under stress.

The key feature of the ME/CFS is post-exertional malaise (PEM), or the failure to recover, or a worsening of symptoms, following minimal physical or mental activity. PEM may not occur immediately; the onset may be delayed. It can persist for hours, days or even weeks. Recovery is often prolonged, lasting days or sometimes weeks to months.

ME/CFS is classified as a disease of the nervous system (WHO International Classification of Diseases: ICD-11 Version: 2019).

The US Centers for Disease Control and Prevention (CDC) recognise ME/CFS as an organic syndrome, not a psychiatric disorder. Although depression and anxiety may occur secondary to the illness, research studies have shown that ME/CFS and major depressive disorders can be distinguished using behavioural, immunological and hormonal testing.

Who gets ME/CFS?

ME/CFS affects people of all ages, including children, and people from all racial and ethnic groups.

What causes ME/CFS?

While the cause of ME/CFS is uncertain, research suggests that both genetic and environmental factors may contribute to the illness. A number of infectious agents have also been found in patients with ME/CFS, but no single infectious agent has been proven to be the cause.

Onset, Progress and Recovery

ME/CFS often starts with acute, 'flu-like' symptoms, and the immune system changes found in ME/CFS are similar to those found in some viral infections. For others, the onset is gradual, over months or years.

Other links being explored include environmental toxins, immunisations, or surviving a major trauma. For a person living with ME/CFS, it is useful to keep a history of how and when the disease began because this helps to identify your particular triggers and thus may inform your management plan.

The lack of a known cause does not mean that the symptoms of the condition cannot be managed.

Management of ME/CFS is aimed at symptom reduction and limiting the progression of the disease. As for any chronic illness it includes medical, allied health and lifestyle interventions.

While there is no single diagnostic test, diagnosis is made clinically from the pattern of symptoms and the exclusion of other illnesses with overlapping symptoms.

The diagnosis of ME/CFS is made clinically using a standard symptom criteria.

Diagnosis requires the following:

- A medical history, a clinical examination, and appropriate medical testing in order to exclude other conditions that might explain the symptoms.
- 2. There is a new onset of unexplained, persistent, or relapsing physical and mental fatigue that has lasted for at least six months and has resulted in substantially reduced activity levels.
- 3. The weakness/fatigue and the accompanying symptoms are not the result of ongoing exertion and are not relieved by rest.
- 4. Post-exertional malaise (PEM), the failure to recover after exertion, particularly after mental and physical activity, that significantly interferes with daily work and activities.
- 5. The diagnostic criteria include a secondary group of symptoms. (Useful questionnaires are available, based on the International ME/CFS or Canadian clinical case consensus definition questionnaires. These cover the multiple symptoms commonly found in patients with ME/CFS).

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The secondary symptoms include

- Unrefreshing sleep, may include night-time insomnia and/or daytime hypersomnia (excessive sleep)
- Chronic Pain, widespread, migratory or localised pain in muscles or joints (without swelling), or headaches of a new type or increased severity
- Neuro-cognitive symptoms, including confusion, impaired concentration, impaired short-term memory, difficulty finding words, disorientation, emotional overload, hypersensitivity to temperature, chemicals, movement, light, noise, and disturbed balance
- Autonomic dysfunction such as orthostatic intolerance (the body does not respond normally to upright posture), neurally mediated hypotension, postural orthostatic tachycardia (POTS), dizziness, facial pallor, palpitations, irritable bowel syndrome, urinary frequency, and shortness of breath.
- Neuroendocrine manifestations including low body temperature, intolerance to heat and cold, feeling feverish, sweating, abnormal appetite, or symptoms that worsen with stress
- Immune dysfunction including tender lymph nodes, recurrent sore throats, recurrent flu-like symptoms, or new sensitivity to food, medications or chemicals
- **Circulatory,** including cardiac arrhythmias, tachycardia (racing heart) or palpitations usually associated with autonomic nervous system dysfunction.

Symptoms fluctuate and vary

The pattern of symptoms varies from patient to patient, and symptoms may vary in severity from day to day or from one part of the day to another. Patients are encouraged to keep a diary to monitor their symptoms and help identify triggers that worsen symptoms. This can guide management steps and priorities.

Relapses

Relapses are common, they are frequently caused by over-exhaustion (PEM, post-exertional malaise), also, any new or ongoing infectious illness, or other triggers. Remissions can occur. Some patients can slowly get worse.

People in relapses or a severe state are managed differently, and with caution; people can be sensitive to treatments and rapid changes may cause further harm.

Early Intervention

Patients may be severe, very ill at the onset of the illness. In many cases the diagnosis is delayed because some diagnostic criteria require six months of symptoms before diagnosis. If a provisional or 'at risk' diagnosis (sometimes called Idiopathic Chronic Fatigue or Post Viral Syndrome) is made before six months have passed, the impact of the condition may be reduced by ensuring that the person has adequate rest and targeted therapy.

Patients with ME/CFS tend to improve slowly and then reach a plateau. At this time, the severity of their illness varies between two extremes, some patients are homebound as well as bedbound, and others are able to go out to work or attend school.

ME/CFS patients who work or attend school may require some reasonable accommodations, and they often need extra rest. When ME/CFS is severe it is common to require a complete absence from work or school.

Recovery rates are uncertain and vary from 5% to 30% in the first five years. After five years, recovery is less likely. Patients in remission still find that they need extra rest.

References:

Caruthers BM et al, 2011 Myalgic Encephalomyelitis: (2011) International Consensus Criteria, Journal of Internal Medicine 2011 v 270 p327-338 Carruthers BM, et al. ME/CFS Clinical working case definition, diagnostic and treatment protocols. J. C F S 2003; 11(1):7-115. International ME/CFS Association Primer for Clinical Practitioners, 2014 Rowe Peter et al, 2017 ME/CFS in Young People: A Primer – Frontiers in Pediatrics 2017