

Should you require any further information or wish to further explore the information provided in this pamphlet, please contact Emerge Australia.

www.emerge.org.au

FAMILY AND FRIENDS

FACT SHEET 3
ENGLISH



Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) 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.

Supported by, ME/CFS
Australia, the
Australian Government
Department of Health
and Ageing

Family and friends

A great asset for people with ME/CFS is to have knowledgeable and supportive people around them.

The name 'chronic fatigue syndrome' can be misleading as often people think that having ME/CFS is just being very tired. This is incorrect. People with ME/CFS generally have a number of physical and neurological symptoms that affect their daily lives over a long period of time.

The severity of ME/CFS varies considerably; some people are bedridden while others are able to manage degrees of activity. Some people with ME/CFS may be able to continue to work and participate in social activities. Some with a mild form may be able to continue working. The severity of ME/CFS can alter over time.

In order to understand the range of symptoms that can be experienced by a person with ME/CFS it is useful to look at the International Consensus Primer for Medical Practitioners (2012) diagnostic criteria:

Compulsory:

Post-Exertional Neuroimmune Exhaustion—The inability to produce sufficient energy on demand characterized by rapid physical and/or cognitive debilitating fatigue in response to minimal exertion (immediate and/or delayed by hours or days) and symptom exacerbation.

In addition to:

Neurological Impairments—At least one symptom from three of the four symptom categories:

1. Neurocognitive—difficulty processing information (confusion, difficulty making decisions, slowed speech, dyslexia), short-term

memory loss (difficulty finding words, names, recalling information, poor working memory)

2. Pain— Headaches, migraine, significant widespread pain non-inflammatory in nature.
3. Sleep Disturbance—disturbed sleep patterns, unrefreshed sleep, vivid dreams/nightmares
4. Neurosensory, Perceptual and Motor Disturbances—vision, sensitivity to light, noise, odour, taste and touch, gross motor disturbances,

Immune, Gastro-intestinal & Genitourinary Impairments— At least one symptom from three of the five symptom categories:

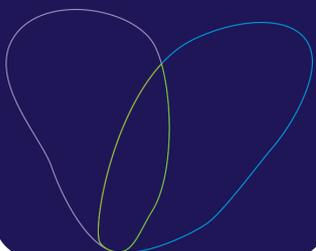
1. Flu-like symptoms—sore throat, sinusitis, enlarged lymph nodes
2. Susceptibility to viral infections with prolonged recovery periods
3. Gastro-intestinal—nausea, bloating, IBS.
4. Genitourinary (e.g urgency and frequency to urinate)
5. Sensitivities to food, medications, odours or chemicals.

Energy Metabolism/Ion Transportation Impairments—At least one symptom

1. Cardiovascular—inability to tolerate upright position, lightheadedness, dizziness, heart palpitations
2. Respiratory—difficulty with breathing
3. Loss of thermostatic stability—subnormal body temperature, sweating, cold extremities, marked fluctuations
4. Intolerance of extremes of temperature

For a full description refer to the Myalgic

“ME/CFS is a delicate balance between energy use and energy production. Learning to fine tune this balance is critical.”



Encephalomyelitis International Consensus Primer for Medical practitioners (2012) downloaded from www.emerge.org.au

People with ME/CFS need to consider changes to their lifestyles to effectively manage their condition. These changes often include incorporating self-help techniques that may seem restrictive or 'anti social' to those unfamiliar with the condition.

It often means that friends and family need to make changes in their expectations of the person with ME/CFS and take cues from their friend or family member as to what activities may be appropriate.

How you can help

Keep yourself informed

Finding out as much about the illness as you can, may be helpful in supporting your friend or family member. Your local ME/CFS Society will have further information available.

Offer practical help

Talk about what help you can offer and allow your friend or family member to direct your assistance or decline if that is what suits them best. Practical help may include a meal preparation or transport to an appointment or the occasional phone call, short visit or email.

Offer non-judgmental acceptance

Providing reassurance to your friend or family member that you are willing to share their journey through ME/CFS without burdening them with your expectations of their treatment or recovery may be the most significant help you can provide.

Adjustments and changes in relationships

Household tasks and roles may need to be redistributed.

Financial adjustments can be overwhelming. Only a few people with ME/CFS are able to continue working full-time. A parent of a young person with ME/CFS will need to change work arrangements to be at home.

Having less energy means reducing time with others and for most will mean a reduction of 50% or more.

Face-to-face contact may need to change to email or telephone. Social outings will need to reduce. Large gatherings may be exhausting. Sensitivity to light, noise and chemicals will lead to further restrictions.

Any stress such as dental work, infections, financial pressures or relationship issues can cause a heightened response.

Travel and holidays are out of the normal routine and use more energy. Travel may be impossible for some. For most it is difficult to adjust to fluctuations in weather/temperature.



Emotions are harder to control with ME/CFS.

People may cry more easily or alternatively they can find laughing exhausting causing brain fog.

Heightened emotions may be a sign that a person has exceeded their activity limit.

Changing expectations

Accepting the loss of 'future dreams' is a significant challenge not only for people with ME/CFS but also for their family and friends.

A key aspect to accepting these changes is to recognise that life has changed.

Acceptance does not mean giving up, but planning to share a different kind of life. It is important to make plans for the best possible life together under the circumstances.

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