



ME/CFS AUSTRALIA

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Should you require any further information or wish to further explore the information provided in this pamphlet, please contact the ME/CFS office in your state or territory.

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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.

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 criteria required for diagnosis.

- 1. Fatigue:** New onset unexplained, physical and mental fatigue. Inappropriate loss of physical/mental stamina.
- 2. Post-exertional malaise:** A pathological slow recovery after both mental and physical function, 24 hours or longer.
- 3. Sleep dysfunction:** Unrefreshing sleep, changed sleep patterns or quantity.
- 4. Pain:** Joint or muscle aches or headaches.
- 5. Neurological-cognitive manifestations,** two or more should be present: Short-term memory problems, poor concentration, word-finding difficulties, inability to calculate numbers, disorientation, difficulty with

processing information, categorising words and word retrieval, perceptual and sensory changes, inability to comprehend/retain what is read, slurring of speech, vision disturbances (blurring, eye pain), numbness, tingling or burning sensations in the extremities, ringing in the ears, balance problems, muscle weakness, overload phenomena either cognitive, sensory or emotional e.g. photophobia or hypersensitivity to noise, touch or sound, which can lead to crash and/or anxiety.

6. At least one symptom from two of the following categories:

6.1 Autonomic: Orthostatic intolerance or difficulty standing, light-headedness, chest palpitations cardiac arrhythmias, shortness of breath, dizziness, pale, nausea, irritable bowel symptoms, bladder dysfunction

6.2 Neuro-endocrine: Changes in body temperature, sweating episodes, cold extremities, marked changes in weight or appetite; symptoms worsen with stress.

6.3 Immune: Tender lymph nodes, sore throat, flu-like symptoms. Allergies and sensitivities to odours, chemicals, medications, low grade fever, rashes.

For a full description refer to the ME/CFS Canadian Clinical Case Definition and Guidelines for Medical Practitioners at <http://www.mecfs.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.

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



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.



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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.

1. Bested, A. 2008 *Chronic Fatigue Syndrome and Fibromyalgia*, 2nd ed. Cumberland House, Nashville
2. Campbell, B. *The Patients guide to chronic fatigue syndrome and fibromyalgia*, CSH Press California
3. De Meirlier, K. 2009, *What causes CFS/ME? Is it all in the gut? Research on extremely disabled ME patients reveals the true nature of the disorder*, Conference, October, Melbourne.
4. Curruthers, B. & van de Sande, M. 2005 *Canadian ME/CFS Clinical Case Definition and Guidelines for Medical Practitioners (Overview)*, Canada.
5. Jason, L. 2006 *A Paediatric Case Definition of ME/CFS*, *Journal of Chronic Fatigue Syndrome*, vol. 13, no. 2/3.
6. Maes, M. & Twisk, F. 2009 *A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS*, *Neuroendocrinology Letters*, vol. 30, no. 3, pp. 284-289.
7. Myhill, S. March 2010, *Diagnosis and treatment of Chronic Fatigue Syndrome 27th edition* www.drmyhill.co.uk
8. Stein, E. 2005 *Clinical Guidelines for Psychiatrists: Assessment and Treatment of Patients with ME/CFS*.

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