

Challenges for people with ME/CFS

Just coping with the myriad of symptoms: Even the simplest task (e.g. sitting) can be challenging.

Emotional: Intractable pain, quality of life issues, the financial/social impact of significant change to lifestyle (working/studying/socialising), grief over loss of previous identity, can all lead to reactive anxiety and depression.

Ignorance: There are still many medical “blanks” about ME/CFS and its treatment. ME/CFS patients often become more knowledgeable about their illness than the health professionals they see.

Disbelief: People with ME/CFS often interact with doctors, family members, friends and acquaintances who are dismissive of the disturbing physical symptoms of ME/CFS or mis-attribute them to psychological illness.

Adjustment: Coping with changed circumstances and developing a new identity as a chronically ill person are substantial challenges.

Hints for people with ME/CFS

- Learn as much as you can about ME/CFS and educate your family and friends
- Listen to your body and pace yourself to balance rest and activity appropriately
- Find an informed/supportive medical practitioner who knows that ME/CFS is not just chronic fatigue
- Seek professional advice about new food intolerances, new sensitivities, diet, nutrition and miracle “cures” for ME/CFS
- Discuss all potential treatments/starting new medications on low doses with your supervising health professional
- Know that mis-diagnosis of ME/CFS is common
- Avoid temperature extremes e.g. hot showers
- Avoid alcohol
- Have regular medical check-ups; ensure new symptoms are thoroughly investigated

Join us today!

The ME/CFS Society of NSW aims to:

- provide information and support to all who are affected by ME/CFS
- promote accurate awareness of ME/CFS within medical and scientific communities and the wider public
- support research into the pathophysiology of ME/CFS

Society membership provides you with:

- M.E. and You journal containing the latest research findings and ideas about how to live with ME/CFS (published four times a year)
- an Annual Report and newsletter (published in December each year)
- access to support groups for sharing of support, information and friendship
- telephone support and information from our Social Welfare Officer

The Society is partially supported by a grant from the NSW Government's Department of Health. The Society does, however, depend on membership fees, fund raising, donations and many volunteers to do its work. By joining the Society, you not only help yourself, but you also help the Society to promote awareness and better medical care for everyone affected by ME/CFS.

To join, contact us

- by telephone: (02) 9904 8433
- by fax: (02) 9904 8435
- in person (telephone first): Suite 204 Level 2, 10 Help Street, Chatswood
- by mail: PO Box 5403 West Chatswood NSW 1515
- by email: mesoc@zip.com.au
- or via our website: www.me-cfs.org.au

Myalgic Encephalopathy – Chronic Fatigue Syndrome (ME/CFS)



“Help Us Break Free”

What is ME/CFS?

ME/CFS is a serious and complex illness that affects multiple systems in the body, but particularly the nervous, endocrine and immune systems.

ME/CFS is much more than just feeling exhausted all the time.

The ME/CFS Society of NSW Inc.

ME/CFS symptoms can include...

◆ Chronic pain

- Whole body, regional or local - aching muscles, joint pain, headaches, chest and/or abdominal pain

◆ Neurological dysfunction

- Impaired concentration and short term memory
- Information processing difficulties and intermittent dyslexia
- Loss of ability to regulate body temperature
- Hypersensitivity to light, sound and/or touch

◆ Immune and Autonomic

- Frequent and/or recurrent infections e.g. flu-like symptoms, sore throat, tender lymph nodes
- Allergies or sensitivities to medications, chemicals and/or foods
- Orthostatic intolerance - sudden drop in blood pressure when changing positions
- Palpitations, tachycardia, arrhythmia, seizures

◆ Disabling weakness and/or fatigue

- Unexplained persistent physical and mental fatigue exacerbated by exertion and requiring extended recovery periods
- Substantial reduction in previous self-care,
- Occupational, educational and social activities
- Post-exertional malaise – worsening of symptoms after physical or mental activity, or stress

◆ Sleep dysfunction

- Altered sleep patterns - inability to fall or stay asleep, circadian rhythm disturbance
- Unrefreshing sleep

◆ Gastrointestinal, urinary and reproductive

- Nausea, vomiting, abdominal pain
- Diarrhoea and/or constipation
- Slow gastric emptying, particularly of fluids
- Urinary disturbances - pain, frequency and urgency
- Menstrual abnormalities

◆ Other symptoms

- Inability to go for long periods without food
- Reactive anxiety, depression, grief, anger, guilt
- Cold extremities

“CFS patients are more sick and have greater consequent disability than patients with chronic obstructive lung disease, cardiac disease, osteoarthritis and depression”

Press release from the October 2004 International Conference of CFS, Fibromyalgia and Related Disorders, co-sponsored by USA's Centers for Disease Control and Prevention and the National Center for Infectious Diseases.

Who gets ME/CFS?

Approximately 3 in every 1000 people within the general community are affected by ME/CFS and 1 in 3000 are severely ill with ME/CFS (Professor John Dwyer, May 2004). Many are confined to their home or bed, isolated from society. It can affect men, women and children of all ages and socioeconomic groups.

There is a higher rate of ME/CFS in women (0.373%), as occurs in all autoimmune diseases, with the highest peak in 50 to 59 year-old women when 1 in 116 is affected.

What causes ME/CFS?

The cause of ME/CFS is not yet known. It usually follows an infection with sudden onset of obvious signs of infection such as sore throat, fever, tender lymph nodes, muscle aches and pains, vomiting and or diarrhoea. There are thought to be up to 30 infections that can trigger ME/CFS in some individuals. ME/CFS can also develop gradually with no apparent trigger.

The onset of ME/CFS, whether it is associated with an infectious trigger or not, is often characterised by symptoms such as cognitive dysfunction, memory and concentration problems, headache, unusual sensitivities to light (photophobia), sounds, some foods, alcohol and medications.

Research is currently directed at understanding the roles of persistent infection, neurological, immune, cardiac, gut and metabolic abnormalities, genetic and environmental factors and stress in causing and or maintaining ME/CFS. “Many blanks remain to be filled in, including nearly all the blanks on treatment” (Dr David S Bell, US paediatrician and Chairperson of the CFS Advisory Committee to the US Government, 2004).

What's the prognosis?

There is little known about the long-term outcomes of ME/CFS. The prognosis for people with ME/CFS ranges from apparent spontaneous recovery (approximately 10% of cases) to remaining seriously ill indefinitely. People with severe ME/CFS can have life-threatening complications.

Statistically, people with fewer and milder symptoms have a better chance of recovery or improvement. Research has shown that, in post-viral ME/CFS, the severity of the initiating infection is the best predictor of how the illness is likely to develop. (Dubbo NSW Infection Outcomes Study.)

Studies have shown that most people improve within three to five years. Many, however, continue to experience symptoms after this time, although usually at a lower level of severity.

Is there a cure for ME/CFS?

There is no single diagnostic test and no known cure. Treatment is directed at individualised support, education and relieving a ME/CFS patient's most problematic symptoms.

Australian doctors are advised to prescribe pain-relief and sleep-modulating medications, cognitive behavioural therapy (CBT) and graded exercise therapy (GET) (2002 Australian Clinical Guidelines for CFS). ME/CFS Societies and their medical consultants have expressed serious concern about the adequacy of the 2002 Australian Guidelines, and especially about the rationale for, and safety of GET in ME/CFS.

In 2004, the South Australian Government published its own Clinical Guidelines for ME/CFS, based upon the Canadian Clinical Criteria, which are better supported by Australian ME/CFS Societies.

International Awareness day is held May 12 each year. Our aim is to teach those around us, our families, friends, school and work colleagues, politicians and our medical professionals more about the illness and the devastating effect it has on sufferers.