

What is ME/CFS?

ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) is severe, complex, acquired illness with symptoms related to the dysfunction of the brain, gastro-intestinal, immune, endocrine and cardiac systems.

ME/CFS is not a psychological illness.

The World Health Organisation (WHO) has classified ME/CFS as a neurological disease since 1969 (ICD 10 G 93.3).

Diagnosis of ME/CFS

The Royal Australasian College of Physicians states that ME/CFS is a real and disabling physical chronic condition, affecting up to 7 per 1000 people.

Up to 38,000 Victorians, 3,500 Tasmanians and 1,600 Northern Territorians live with ME/CFS.

There is no simple diagnostic test.

Diagnosis is based on seven criteria contained with the Canadian Clinical Case Definition and Guidelines (Curruthers et al, 2005) available from www.mecfs-vic.org.au.

Treating ME/CFS

There is no known cure for ME/CFS.

The focus is on easing symptoms.

It is important to find an ME/CFS medical expert who will support and provide effective medication and treatments.

Self-management can be vital. Tests confirming food intolerances and gut abnormalities are critical first steps.

Learning to “pace” is critical to help move towards recovery.



Causes of ME/CFS

Causes of ME/CFS are not yet known. Multiple factors may be simultaneously involved.

ME/CFS can follow:

- . Acute infection, such as glandular fever, upper respiratory infections;*
- . A 'Flu-like' illness;*
- . Exposure to chemicals, environmental pollutants or heavy metals;*
- . Immunisation; and*
- . Severe physical trauma, such as major surgery, or a serious accident.*

Biomedical research is being conducted on many fronts: cardiology, immunology, endocrinology, neurology and genetics.

Symptoms of ME/CFS

The following list of symptoms are drawn from 'An overview of the Canadian Consensus Document: A Clinical Case Definition and Guidelines for Medical Practitioners'.

- **Fatigue;***
- **Post-exertional malaise and/or fatigue;***
- **Dysfunctional sleep;***
- **Pain;***
- **Neurological/cognitive manifestations;***
- **Autonomic manifestations;***
- **Neuroendocrine manifestations;***
- **Immune manifestations; and***
- **The illness must persist for at least six months (three months in children).***

ME/CFS usually has a distinct onset, although it may be gradual. An early diagnosis is possible.



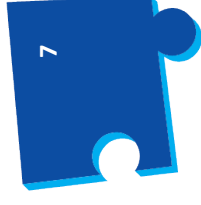
Living with ME/CFS

People with ME/CFS face many challenges.

Apart from the physical limitations, the illness influences social and family life as well as educational and employment opportunities.

Many are too unwell to work and others can work only part-time; social contact can be non-existent.

Young people may find it hard to study and require special consideration for school attendance, assignment deadlines and exams. Some study at home through distance education.



Living with ME/CFS

Some people with ME/CFS have well periods followed by periods with severe symptoms.

The more severely affected are housebound and may require a wheelchair for mobility.

The most severely affected are bedridden and totally dependent on others for all care.

Duration of ME/CFS

Accurate predictions of recovery for individuals are not possible at this stage.

Early diagnosis may lessen the impact of the illness.

Support and acceptance from family and friends is critical.

Some make gradual progress and recover well but many do not completely regain their previous level of health.

Some experience a gradual deterioration in their condition.

Severity of ME/CFS

Severe ME/CFS can be life threatening.

The recovery rate for children is often better than for adults.

People diagnosed with ME/CFS can generally expect to be unwell for some years.

For some it is permanent. Others may require a wheelchair or are bedbound, requiring 24 hour care.



Management of ME/CFS

Learning to 'pace' and live within your 'energy envelope' is critical for improvement.

Using a 'push crash' cycle will make the condition worse.

For support in managing your ME/CFS, please contact ME/CFS Australia (Vic/Tas/NT) on (03) 9791 3100 or visit the website at www.mecfs-vic.org.au.

ME/CFS Vic, Tas, NT

ME/CFS Australia (Vic, Tas, NT) provides information, support and advocacy for people with ME/CFS, their families, friends, carers and health practitioners in Victoria, Tasmania and the Northern Territory.

Services include:

- ‘Emerge’ quarterly journal;*
- Information and support Line;*
- Regular informative E-Bulletin;*
- Self-help courses;*
- Health Practitioners Directory;*
- Local support groups;*
- ‘Link Up’ teleconference sessions;*
- Education forums and seminars;*
- Awareness raising initiatives;*
- Resource library;*
- Advocacy and political lobbying to find a cure.*

Emerge Journal

ME/CFS Australia (Vic, Tas, NT) produces a quarterly journal entitled 'Emerge', which contains reader-submitted articles, support information and the latest medical updates and research on ME/CFS.

'Emerge' is available with membership to ME/CFS Australia (Vic, Tas, NT).

EMERGE

Autumn 2011



**Quarterly journal of
ME/CFS Australia (Vic, Tas, NT)**

Canadian Guidelines

The 'Canadian Guidelines' provide critical diagnosis and support information for medical practitioners. These are the only internationally accepted diagnostic guidelines.

Please contact ME/CFS Australia (Vic, Tas, NT) for a copy on (03) 9791 3100 or visit www.mecfs-vic.org.au.

**Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome:**

**A Clinical Case Definition
and Guidelines for
Medical Practitioners**

An Overview of the Canadian
Consensus Document

Bruce M. Carruthers
Marjorie I. van de Sande

Support Groups

ME/CFS support groups run at various locations across Victoria, Tasmania and the Northern Territory. Support groups are located in:

Melbourne

- *Bentleigh/Bayside*
- *Croydon*
- *Dandenong*
- *Donvale-Mitcham*
- *Frankston*
- *Glen Waverley*
- *Northcote*
- *Richmond*
- *San Remo*
- *St Kilda*
- *Western Suburbs*

Country Victoria

- *Albury/Wodonga*
- *Ballarat*
- *Bendigo*
- *Castlemaine*
- *East Gippsland/Sale*
- *Geelong*
- *San Remo*
- *Shepparton*

Tasmania

- *Devonport*
- *Hobart*
- *Launceston*

Northern Territory



Self-Help Courses

ME/CFS self-help courses provide strategies for those with ME/CFS and Fibromyalgia to help improve the quality of their lives.

ME/CFS Australia (Vic, Tas, NT) run these courses four times a year in person and via teleconference.



Volunteers

ME/CFS Australia (Vic, Tas, NT) relies on the generosity and skills of volunteers to provide its services to the community.

Volunteer tasks include:

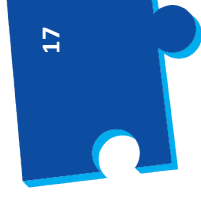
- . Administration support work*
- . Staffing the telephone support line*
- . Developing databases/contact lists*
- . Organising member forums*

If you are interested in volunteering with ME/CFS Australia (Vic, Tas, NT), please call the office on (03) 9791 3100.



Psychiatrist Guidelines

The guidelines for psychiatrists in supporting people with ME/CFS is a critical document, clarifying that ME/CFS is not a psychological disorder.

A rectangular box containing the slide's content. It features a yellow header bar with the title 'CHRONIC FATIGUE SYNDROME', a red circle, and a subtitle. The author's name and credentials are listed at the bottom. The background of the box is light purple with a yellow horizontal line.

CHRONIC FATIGUE SYNDROME

Assessment and Treatment
of Patients with ME/CFS:
Clinical Guidelines for Psychiatrists

Eleanor Stein MD FRCP(C)

Professional Education

ME/CFS Australia (Vic, Tas, NT) provides professional education services to allied health and community workers to support their practice in appropriately managing people with ME/CFS.

Please phone (03) 9791 3100 to book a session with your work team.



Political Lobbying

Political lobbying is a key activity of ME/CFS Australia (Vic, Tas, NT) aimed at advancing the interests of people with ME/CFS through:

- . Formal recognition of ME/CFS as a neurological disability;*
- . Appropriate funding for biomedical research into ME/CFS; and*
- . Appropriate funding for support services.*

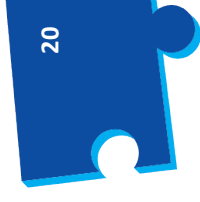
Fundraising

ME/CFS Australia (Victoria) coordinates a number of fundraising campaigns each year, including one-off events and the selling of products.

Donations are always welcome.

Products currently available include:

- Wristbands
- Blue ribbons
- T-shirts
- Pens
- Temporary tattoos



***If you would like further
information or support please
contact ME/CFS Australia (Vic, Tas, NT) on:***

Phone: (03) 9791 3100

Support Line: (03) 9791 2199

Website: www.mecfs-vic.org.au

Please take a brochure.

If you are calling from interstate please let the office staff know.

They will call you back to reduce your call costs.

