

# ME/CFS Guidelines

## Myalgic Encephalopathy (ME)/ Chronic Fatigue Syndrome (CFS)

Management Guidelines for General Practitioners

A guideline for the diagnosis and management of ME/CFS  
in the community or primary care setting



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Government  
of South Australia



Adelaide Western  
Division of  
General Practice



2004

#### Disclaimer

These guidelines have been developed, where possible, by achieving consensus between practising clinicians. The recommendations contained in these guidelines do not indicate an exclusive course of action, or serve as a standard of medical care. Variations, taking individual circumstances into account, may be appropriate.

The authors of these guidelines have made considerable efforts to ensure the information upon which they are based is accurate and up to date. The authors accept no responsibility for any inaccuracies, information perceived as misleading, or the success of any treatment regimen detailed in the guidelines.

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This publication uses the term Myalgic Encephalopathy rather than the less accepted term Myalgic Encephalomyelitis.

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# INTRODUCTION

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) is a not uncommon medical disorder that causes significant ill health and disability in sufferers.

It is now officially recognised by the World Health Organization International Classification of Diseases, and by recent international and Australian guidelines on ME/CFS.

ME/CFS is also known by other names such as Post Viral Fatigue Syndrome.

ME/CFS is characterised by severe, disabling fatigue and post-exertional malaise. Other symptoms include:

- ◆ Muscle aches and pain
- ◆ Unrefreshing sleep or altered sleep patterns
- ◆ Neuro-cognitive dysfunction (e.g. poor concentration and memory)
- ◆ Gastro-intestinal symptoms (e.g. irritable bowel)
- ◆ Orthostatic intolerance (e.g. low blood pressure)
- ◆ Unusual headaches

A hallmark of the condition is that symptoms are usually worsened with minimal physical and mental exertion.

Many medical practitioners are not confident in diagnosing and managing ME/CFS patients. This may lead to a difficult doctor – patient relationship, poor management of the condition and less than adequate outcomes for patients (and their carers).

ME/CFS guidelines have been developed in Australia and overseas in the past, but GPs have made little use of them because of their bulk, lack of clarity and associated controversy.

A taskforce of South Australian clinicians and others with experience in ME/CFS have developed this more succinct set of guidelines for GPs and other medical practitioners. Its focus is on the basic diagnosis and management of this condition in the community or primary care setting.

The prognosis for ME/CFS is variable. Most patients will generally improve functionality to some degree over time, usually 3 to 5 years. However, symptoms may fluctuate or relapses may occur from time to time. Early intervention and positive diagnosis often result in better prognosis. However, a significant proportion of patients will remain quite debilitated for longer periods of time.

ME/CFS is officially recognised by the World Health Organization International Classification of Diseases.

Early intervention and positive diagnosis often result in better prognosis.

# CANADIAN CLINICAL CRITERIA (abbreviated version) 2003

**It is recommended that this tick chart be used in the initial consultation to assist with a possible diagnosis of ME/CFS. (NB: Sections 1 to 6 must all be met as indicated below)**

## 1) Post-Exertional Malaise and Fatigue:

(All criteria in this section must be met)

- a) The patient must have a marked degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level .....
- b) Post-exertional fatigue, malaise and/or pain, and a delayed recovery period (more than 24 hours to recover) .....
- c) Symptoms can be exacerbated by exertion or stress of any kind .....

## 2) Sleep Disorder:

(This criterion must be met)

Unrefreshing sleep or altered sleep pattern (including circadian rhythm disturbance) .....

## 3) Pain:

(This criterion must be met)

Arthralgia and/or myalgia without clinical evidence of inflammatory responses of joint swelling or redness, and/or significant headaches of new type, pattern, or severity .....

## 4) Neurological/Cognitive Manifestations:

(Two or more of the following criteria must be met)

- a) Impairment of concentration and short-term memory .....
- b) Difficulty with information processing, categorizing, and work retrieval, including intermittent dyslexia .....
- c) There may be an overload phenomena: information, cognitive, and sensory overload (e.g. photophobia and hypersensitivity to noise) and/or emotional overload which may lead to relapses and/or anxiety .....
- d) Perceptual/sensory disturbances .....
- e) Disorientation or confusion .....
- f) Ataxia .....

## 5) Autonomic/Neuroendocrine/Immune Manifestations:

(At least one symptom in at least two of the following three categories must be met):

### A) Autonomic Manifestations:

- 1) Orthostatic Intolerance (e.g. neurally mediated hypotension (NMH)) .....
- 2) Postural orthostatic tachycardia syndrome (POTS) .....
- 3) Vertigo and/or light-headedness .....
- 4) Extreme pallor .....
- 5) Intestinal or bladder disturbances with or without irritable bowel syndrome (IBS) or bladder dysfunction .....
- 6) Palpitations with or without cardiac arrhythmia .....
- 7) Vasomotor instability .....
- 8) Respiratory irregularities .....

### B) Neuroendocrine Manifestations:

- 1) Loss of thermostatic stability .....
- 2) Heat/cold intolerance .....
- 3) Anorexia or abnormal appetite, weight change .....
- 4) Hypoglycemia .....
- 5) Loss of adaptability and tolerance for stress, worsening of symptoms with stress and slow recovery, and emotional lability .....

### C) Immune Manifestations:

- 1) Tender lymph nodes .....
- 2) Recurrent sore throat .....
- 3) Flu-like symptoms and/or general malaise .....
- 4) Development of new allergies or changes in status of old ones .....
- 5) Hypersensitivity to medications and/or chemicals .....

## 6) The illness persists for at least 6 months:

(This criterion must be met) .....

NB: ME/CFS usually has an acute onset, but onset may also be gradual. A preliminary diagnosis may be possible in the early stages. The disturbances generally form symptom clusters that are often unique to a particular patient. The manifestations may fluctuate and change over time.

# DEFINITION OF ME/CFS

There are many definitions of ME/CFS. The Fukuda Criteria (1994) is still considered the international benchmark for use in ME/CFS research, and is often used as a de facto clinical definition. However many see the criteria as being vague and over inclusive (e.g. Jason 2000). Furthermore, they downplay (i.e. make optional) post-exertional malaise and other cardinal ME/CFS symptoms.

The term Chronic Fatigue Syndrome may convey the perception that sufferers are simply overtired. However, fatigue is just one of a multitude of symptoms.

The Canadian Expert Consensus Panel published the first diagnostic ME/CFS criteria for clinical use in 2003. In contrast to the Fukuda Criteria, this new definition made it compulsory that to be diagnosed with ME/CFS, a patient must become symptomatically ill after minimal exertion. It also clarified other neurological, neurocognitive, neuroendocrine, autonomic, and immune manifestations of the condition.

A modified tick chart of the Canadian Clinical Criteria is included in this document. (Pages 5 and 14.)

It is recommended that it be used in the initial consultation to assist with the diagnosis of ME/CFS.

## Co-existing Conditions

ME/CFS may co-exist with or mimic symptoms associated with:

- Fibromyalgia
- Multiple Chemical Sensitivity
- Irritable Bowel Syndrome
- Depression
- Anxiety disorders
- Somatoform disorders

This can make diagnosis of ME/CFS and any co-existing conditions difficult.

If a positive diagnosis of ME/CFS cannot be determined, then a specialist referral for further assessment would be appropriate.

## Depression and ME/CFS

Some of the symptoms seen in ME/CFS overlap significantly with those in other neuro-psychiatric disorders such as depression and anxiety.

Furthermore, depression (and particularly reactive depression) and anxiety may often co-exist with ME/CFS.

Nonetheless there are significant differences between these overlapping entities. Unlike depressed patients, ME/CFS sufferers are usually highly motivated to do things. They suffer no loss of pleasure gained from usual daily activities and their self-esteem is intact.

They exhibit post-exertional malaise in response to minimal effort, orthostatic intolerance and a range of cognitive impairments and other neurological symptoms not usually associated with depression.

ME/CFS sufferers also report bouts of 'extreme frustration' or situational depression because of the restrictions the condition places on their family, social and work place relationships.

## Exclusion Criteria

The following is a sample of some other conditions (differential diagnosis) that may need exclusion:

- Hypothyroidism
- Hyperthyroidism
- Diabetes Mellitus
- Addison's disease
- Coeliac disease
- Anaemia
- Haemochromatosis
- Systemic Lupus Erythematosus
- Polymyalgia Rheumatica
- Sarcoidosis
- Multiple Sclerosis
- Parkinson's disease
- Sleep Apnoea Syndrome
- Myasthenia Gravis
- Rare myopathies
- Malignancy
- Hypercalcaemia
- Lyme disease
- Chronic Hepatitis
- HIV/AIDS
- Fibromyalgia
- Major Depression
- Anxiety Disorders
- Somatoform disorders

Fatigue is just one of a multitude of symptoms

# EPIDEMIOLOGY

ME/CFS affects all social and ethnic groups.

There is a predominance of females (2 to 1) and a bimodal distribution with peaks between 15-20 year olds and 33-45 year olds.

The prevalence of ME/CFS varies between 0.2% and 0.5% of the total population. In South Australia this translates to between 3,000 and 7,000 cases at any one time.

## AETIOLOGY AND PATHO-PHYSIOLOGY

The causes of ME/CFS are not well understood. The patho-physiological basis of ME/CFS is complex because of the multi-system involvement and multiple symptoms of varying intensity. Further research is clearly needed to ascertain the complex patho-physiological basis of ME/CFS.

The onset may be acute or gradual. There may also be a number of triggering factors present, such as an acute infection and / or significant life events.

Most of the ME/CFS research to date points to central nervous system dysfunction associated with autonomic, neuro-endocrine, neuro-psychiatric and immunological disturbances. SPECT and PET scanning research has highlighted hypo-perfusion and altered function within deep structures of the brain, but the evidence is inconclusive.

Alterations to cell membrane functioning and altered biochemical markers are also advocated, but again the evidence is not conclusive. However, neuromuscular performance in people with ME/CFS had been shown to be normal.

ME/CFS affects all social and ethnic groups.

Further research is clearly needed to ascertain the complex patho-physiological basis of ME/CFS.

# PATIENT EVALUATION

A positive diagnosis of ME/CFS is an important first step in the management of this condition.

The diagnosis is based on recognising the pattern of characteristic symptoms of ME/CFS and excluding alternative diagnoses. An interim diagnosis can be established within six months from the onset of symptoms to allow earlier intervention and management. If symptoms persist beyond six months then the diagnosis can be confirmed.

A positive diagnosis of ME/CFS is an important first step in the management of this condition.

## History

The history of the patient's condition often provides most of the information needed to make a diagnosis. Patients must be given sufficient time to present a full account of their symptoms, factors that worsen or improve them and a comparison with previous healthy functioning.

For women, symptoms may worsen at certain times of the menstrual cycle (e.g. pre-menstrual), while pregnancy appears to alleviate symptoms in some women.

Onset, duration and variability of symptoms over time should be ascertained.

The hallmark of ME/CFS is that increased physical or mental exertion results in worsening symptoms, often with a delayed impact (i.e. it is felt later the same day or next day), and lasting for more than 24 hours. Recovery from such relapses may take days, weeks or even months.

## Physical Examination

Often no significant abnormality is noted.

Some patients may have tender lymph glands, localised tender points in muscles, resting tachycardia, low blood pressure or low body temperature.

The physical examination will also assist with excluding other conditions.

## Mental State Assessment

This is important in order to determine if other co-morbidities exist. Reactive depression can often co-exist or interact with the patient's ME/CFS. Many patients live in a depressing situation because of the severe restrictions on their home, work and social life.

Useful questionnaires and other assessment tools include:

- Mini-mental test
- Neuro-psychological tests
- Depression and Anxiety assessment tools

## Investigations

There is no single abnormality that is specific for ME/CFS, however the basic screening tests help to exclude major non-ME/CFS causes of fatigue.

Basic screening tests: CBP; ESR; MBA20; Fasting BSL; TSH; Urine analysis; Fe studies (for women).

Further testing may be undertaken as clinically indicated to exclude other non-ME/CFS causes. Alternatively, seek specialist/expert support and advice.

# APPROACH TO MANAGEMENT

All treatment should be patient-centred and involve supportive counselling, lifestyle management and the setting of realistic goals.

There is no known cure for ME/CFS. Management is geared at improving functionality and symptom control through an effective therapeutic alliance between the patient and their GP.

For patients who are severely disabled, bed-ridden or not responding to the basic management as outlined below, please consider referral to a specialist or GP with expertise in the condition.

All patients will require ongoing assessment, education, support and encouragement. They should also have regular health checks for other conditions. New symptoms may not be due to ME/CFS and should be investigated further.

Management is geared at improving functionality and symptom control.

## Activity Management

- **Budget physical and mental activity:**
  - ◆ Patients should gently and gradually increase their level of activity (e.g. gentle walking, hydrotherapy and stretching exercises).
  - ◆ Patients should learn to set boundaries, prioritise activities, and pace themselves without overdoing it on a 'good day'. Otherwise they risk triggering a relapse of symptoms.
  - ◆ If it takes more than 30-60 minutes to recover from activity, then the patient is probably overdoing it.
  - ◆ Unless severely affected, it is important that patients avoid prolonged bed rest.
  - ◆ A pedometer can help monitor progress with increasing levels of activity.
  - ◆ It may be useful to refer the patient to a physiotherapist or occupational therapist for further assessment and advice on activity management.

## Symptom Control

- **Poor sleep:**
  - ◆ Basic sleep hygiene principles are very important. Patients should avoid daytime naps, try to get to bed at a reasonable hour at night and keep to a regular schedule.
  - ◆ A low dose TCA (Tricyclic Antidepressant) such as amitriptyline, nortriptyline or doxepin (5 to 25mg) may assist with sleep.
  - ◆ Alternatives include St John's Wort, valerian and doxylamine (e.g. Restavit, Docile).
  - ◆ Hypnotics may be useful in establishing normal sleep pattern, but their long-term use should be avoided.
- **Muscle aches and headaches:**
  - ◆ Low dose TCA's, simple analgesics, and/or anti-inflammatories may help.
  - ◆ Tramadol may help in some patients.
  - ◆ For more severe pain consider pain management clinic assessment and advice.
  - ◆ Anticonvulsants may be helpful in some cases.
- **Muscle twitching or cramps:**
  - ◆ Consider muscle relaxants (e.g. diazepam or baclofen).
- **Gastrointestinal symptoms:**
  - ◆ Some patients may need to exclude certain offending foods (usually wheat and/or dairy products).
  - ◆ For upper GI symptoms (bloating, nausea), patients should avoid offending foods and have regular small meals. Avoid fluids one hour before, during and after meals, because of delayed gastric emptying of liquids in ME/CFS patients.
  - ◆ It might be useful to refer the patient to a dietician, gastro-enterologist or allergist for further assessment.

- **Orthostatic intolerance** (low blood pressure/resting tachycardia):
  - ◆ A simple heart monitor can help with feedback when the heart rate indicates excessive response to minimal activity, and hence the need to reduce activity.
  - ◆ Adequate hydration must be maintained.
  - ◆ Pressure garments on lower limbs and abdomen might also help ambulation.
- **Mood disorders** (e.g. reactive depression and anxiety):
  - ◆ Counselling is helpful in most cases.
  - ◆ Cognitive Behaviour Therapy (CBT) by a trained psychologist or psychiatrist can be useful for those not coping with their illness and who may benefit from CBT. CBT assumes that what we think and do impacts on any illness experience. Therefore, individuals can alter negative patterns with help from trained therapists (e.g. CBT may assist with activity management, sleep hygiene, goal setting and dealing with reactions to illness or relapses).
  - ◆ If medications are required, consider: St John's Wort, Sertraline 50mg, Citalopram 20mg, or Venlafaxine 75mg initially.
  - ◆ Referral to a psychiatrist may also be required for further assessment.

## Other General Principles

Carer support and education are essential.

**Avoid social withdrawal:** Patients should be encouraged to keep up with social networking/support, even if only by telephone.

**Stress reduction techniques:** (e.g. meditation and gentle massage therapy) are often helpful.

**Avoid or manage aggravators or triggers:** (e.g. overexertion, surgery, anaesthetics, vaccinations, chemicals, air travel) that may cause relapses.

**Medication:** Start with a low dose of any medications since the usual doses are often poorly tolerated.

### Healthy eating and drinking:

- ◆ Patients may need to increase their protein intake to say 35% (e.g. lean meat, chicken, fish, etc), eat low Glycaemic Index carbohydrates - up to 55%, and eat good fats (at least 10%).
- ◆ Avoid alcohol, caffeine, and other foods that are not tolerated (e.g. that cause irritable bowel, nausea or bloating) or worsen their symptoms.
- ◆ A referral to a dietician may be required.
- ◆ Adequate daily intake of fluid is essential.

### Complementary therapies:

- ◆ Most patients with this condition will try other therapies at some time and should be advised to discuss these with their doctor. There is no evidence to suggest they are curative, but there are some claims that they may assist with symptomatic relief.
- ◆ Patients have reported remedial benefits from massage therapy, hydrotherapy and acupuncture, as well as from fish oils (e.g. Efamol Marine) and Magnesium supplements.
- ◆ If vitamin supplements are required one multivitamin is often sufficient.

**Surgery:** Patients undergoing surgery may avoid relapses if they are kept slightly overhydrated and are given oxygen supplementation post-operatively.

**Travel:** Patients often become exhausted with long-distance car or air travel (even as passengers). Some patients have been able to tolerate air travel if they remain well hydrated and have in-flight oxygen supplementation (e.g. 2 to 3 litres/minute).

**Pregnancy:** ME/CFS is usually not adversely affected by pregnancy. However, exacerbations are common in the post-natal period.

# PATIENT MONITORING AND SELF MANAGEMENT

It is important that ME/CFS sufferers set realistic goals, and monitor and record improvements in managing their condition.

Examples include:

- ◆ Keeping a diary of treatments tried and their effects.
- ◆ Using the David Bell Disability scale to measure progress from a subjective perspective.

- ◆ Recording things that they have done, how long it may take to do things, distances walked (e.g. use a pedometer), etc.

Patients should be encouraged to seek further information from appropriate websites/books (see Page 16) and to participate in self-management courses.

## CHILDREN AND YOUNG PEOPLE

Children and young people may be too unwell to attend their school or university for long periods of time. Open Access schooling is an option for some students. A letter of support to their educational institution could suggest restrictions to some activities - sporting and camp activities for example, as well as extra time to complete

assignments or sit exams (with rest breaks). In some cases it may be more appropriate to suggest exams be shortened in length or spread over a couple of days.

A referral to a paediatrician may also be appropriate.

## PROGNOSIS

The prognosis for ME/CFS patients is variable. Most will generally improve in functionality to some degree over time, usually 3 to 5 years. However, symptoms may fluctuate or relapses may occur from time to time. Early intervention and positive diagnosis often result in a better prognosis. However, a significant proportion of

patients will remain quite debilitated for longer periods of time.

Symptoms may fluctuate or relapses may occur from time to time.

## BURDEN OF ME/CFS

This condition can severely disrupt a person's social activities, study and/or productive work. Many sufferers face significant social and economic hardships. Their quality of life often diminishes more severely than in many other chronic illnesses. The community costs in Australia are very high.

The impact on partners, other family members or carers can also be significant, with the potential to put relationships under strain. Support and counselling for carers or family members are strongly recommended where appropriate.

GPs can also assist with access to Centrelink (e.g. Disability Support and Carer Support) payments, as well as early access to superannuation funds where a patient faces financial hardship.

Severely affected patients (those who are house or bed bound) may require home visits and assessments and the involvement of the other healthcare professionals and social services. Respite care in accepting institutions may be required from time to time. Very few research studies have been done involving such patients.

## CASE EXAMPLES

The case examples below have been adapted from *Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses – The Comprehensive Guide* by Katrina Berne.

### Case Example 1:

Jane was an active, energetic (Type A personality) accountant who woke up one morning with a sore throat, tender lymph nodes, malaise and achiness. She assumed these symptoms would clear up in a few days or weeks. After a short time she returned to work and tried to push her way through her feelings of exhaustion but ended up having to discontinue her job. Two years later Jane spends most of her time in bed, no longer able to fulfil her former responsibilities at work or at home. Minor household chores and basic personal grooming require almost superhuman effort. Her symptoms worsen if she pushes herself. She says her mind cannot focus and she aches all over but all her medical tests have been normal.

### Case Example 2:

Fourteen year old Sandra was once a straight 'A' student but has had to leave school because she feels exhausted all the time and cannot sit up or think straight. She was initially diagnosed with school phobia and forced to attend school, becoming sicker every day. Now she attends two classes per day, is excused from physical education and is home-tutored for her other classes. She looks forward to school but is often unable to attend even for a few hours.

# APPENDIX 1 DAVID BELL CFS DISABILITY SCALE

Can be used by both patient and doctor to monitor progress/relapses of this condition

100

No symptoms at rest; no symptoms with exercise; normal overall activity level; able to work full-time without difficulty.

90

No symptoms at rest; mild symptoms with activity; normal overall activity level; able to work full-time without difficulty.

80

Mild symptoms at rest; symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.

70

Mild symptoms at rest; some daily activity limitation clearly noted; overall functioning close to 90% of expected except for activities requiring exertion; able to work full-time with difficulty.

60

Mild to moderate symptoms at rest; daily activity limitation clearly noted; overall functioning 70% - 90%; unable to work full-time in jobs requiring physical labour, but able to work full-time in light activities if hours flexible.

50

Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected; unable to perform strenuous duties, but able to perform light duty or desk work 4-5 hours a day, but requires rest periods.

40

Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall level reduced to 50% - 70% of expected; not confined to house; unable to perform strenuous duties; able to perform light duty or desk work 3-4 hours a day but requires rest periods.

30

Moderate to severe symptoms at rest; severe symptoms with any exercise; overall activity level reduced to 50% of expected; usually confined to house; unable to perform strenuous tasks; able to perform desk work 2-3 hours a day, but requires rest periods.

20

Moderate to severe symptoms at rest; severe symptoms with any exercise; overall activity level reduced to 30% - 50% of expected; unable to leave house except rarely; confined to bed most of day; unable to concentrate for more than 1 hour a day.

10

Severe symptoms at rest; bedridden the majority of the time; no travel outside of the house; marked cognitive symptoms preventing concentration.

0

Severe symptoms on a continuous basis; bedridden constantly; unable to care for self.

From: *The Doctor's Guide to Chronic Fatigue Syndrome* by David Bell

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## APPENDIX 2 CANADIAN CLINICAL CRITERIA

**It is recommended that this tick chart be used in the initial consultation to assist with a possible diagnosis of ME/CFS. (NB: Sections 1 to 6 must all be met as indicated below)**

### 1) Post-Exertional Malaise and Fatigue:

(All criteria in this section must be met)

- a) The patient must have a marked degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level .....
- b) Post-exertional fatigue, malaise and/or pain, and a delayed recovery period (more than 24 hours to recover) .....
- c) Symptoms can be exacerbated by exertion or stress of any kind .....

### 2) Sleep Disorder:

(This criterion must be met)

- Unrefreshing sleep or altered sleep pattern (including circadian rhythm disturbance) .....

### 3) Pain:

(This criterion must be met)

- Arthralgia and/or myalgia without clinical evidence of inflammatory responses of joint swelling or redness, and/or significant headaches of new type, pattern, or severity .....

### 4) Neurological/Cognitive Manifestations:

(Two or more of the following criteria must be met)

- a) Impairment of concentration and short-term memory .....
- b) Difficulty with information processing, categorizing, and work retrieval, including intermittent dyslexia .....
- c) There may be an overload phenomena: information, cognitive, and sensory overload (e.g. photophobia and hypersensitivity to noise) and/or emotional overload which may lead to relapses and/or anxiety .....
- d) Perceptual/sensory disturbances .....
- e) Disorientation or confusion .....
- f) Ataxia .....

### 5) Autonomic/Neuroendocrine/Immune Manifestations:

(At least one symptom in at least two of the following three categories must be met):

#### A) Autonomic Manifestations:

- 1) Orthostatic Intolerance (e.g. neurally mediated hypotension (NMH)) .....
- 2) Postural orthostatic tachycardia syndrome (POTS) .....
- 3) Vertigo and/or light-headedness .....
- 4) Extreme pallor .....
- 5) Intestinal or bladder disturbances with or without irritable bowel syndrome (IBS) or bladder dysfunction .....
- 6) Palpitations with or without cardiac arrhythmia .....
- 7) Vasomotor instability .....
- 8) Respiratory irregularities .....

#### B) Neuroendocrine Manifestations:

- 1) Loss of thermostatic stability .....
- 2) Heat/cold intolerance .....
- 3) Anorexia or abnormal appetite, weight change .....
- 4) Hypoglycemia .....
- 5) Loss of adaptability and tolerance for stress, worsening of symptoms with stress and slow recovery, and emotional lability .....

#### C) Immune Manifestations:

- 1) Tender lymph nodes .....
- 2) Recurrent sore throat .....
- 3) Flu-like symptoms and/or general malaise .....
- 4) Development of new allergies or changes in status of old ones .....
- 5) Hypersensitivity to medications and/or chemicals .....

### 6) The illness persists for at least 6 months:

(This criterion must be met) .....

NB: ME/CFS usually has an acute onset, but onset may also be gradual. A preliminary diagnosis may be possible in the early stages. The disturbances generally form symptom clusters that are often unique to a particular patient. The manifestations may fluctuate and change over time.

# ACKNOWLEDGEMENTS

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5. Bell, D *The Doctor's Guide to Chronic Fatigue Syndrome*. Addison-Wesley Publishing Company, Reading, Mass., 1996.

## FURTHER INFORMATION

### Publications

1. MacIntyre, A. *M.E. Chronic Fatigue Syndrome: a practical guide*. Thorsons, London, 1998.
2. *The Chief Medical Officer's Working Group Report on CFS/ME*. Department of Health, UK, 2001.
3. RACP Working Group. *Chronic Fatigue Syndrome – Clinical Practice Guidelines*. MJA Vol 176 Supplement, May 2002.
4. Shepherd, C and Chaudhuri, A. *ME/CFS/PVFS: An exploration of the key clinical issues*. ME Association (UK), June 2001.
5. Bell, David S. *The Doctor's Guide to Chronic Fatigue Syndrome*. Addison-Wesley Publishing Co. Reading, Mass 1995. ISBN:0201407973.
6. Lewis, Donald P. *Turning Disability Toward Ability: Understanding Concepts related to CFS/ME*. CFS Discovery, Victoria, 2003. ISBN:0-9750712-03.
7. Berne, K. *Chronic Fatigue Syndrome, Fibromyalgia and Other Invisible Illnesses – The Comprehensive Guide*. Hunter House Publishing, 2002.

### Community Support Groups

ME/CFS Society (SA) Inc. ([www.sacfs.asn.au](http://www.sacfs.asn.au))

- Administration Tel: (08) 8410 8929
- Support and Information Tel: (08) 8410 8930 (Mon, Wed, Thu: 10am to 4pm)
- Country callers: 1800 136 626

Disability Information and Resource Centre  
([www.dircsa.org.au](http://www.dircsa.org.au))

195 Gilles Street, Adelaide, SA

- Library has many ME/CFS resources for loan
- Tel: (08) 8236 0555
- Country callers: 1300 305 558

Carers Association of SA Inc

([www.carers-sa.asn.au](http://www.carers-sa.asn.au))

- Tel: 1800 815 549

Fibromyalgia SA (A branch of the Arthritis Foundation)

([www.arthritissa.org.au](http://www.arthritissa.org.au))

- Tel: (08) 8379 5711
- Helpline: 1800 011 041

### Websites

Helpful websites with comprehensive resources for ME/CFS include:

[www.sacfs.asn.au](http://www.sacfs.asn.au)

[www.co-cure.org](http://www.co-cure.org)

[www.ahmf.org](http://www.ahmf.org)

[www.afme.org.uk](http://www.afme.org.uk)