



Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS): Basic Facts for General Practitioners

What is ME/Chronic Fatigue Syndrome?

ME/CFS is a debilitating disease that can be triggered by viral infection, chemical exposure or major trauma; the onset may be sudden or gradual. It can effect every system of the body in varying degrees, resulting in a wide range of symptoms. ME/CFS is characterised by:

- persistent fatigue not alleviated by rest
- profound exhaustive fatigue following little exertion (mental and physical)
- poor memory and concentration
- unrefreshing and disrupted sleep

The causal mechanism and the exact nature of the condition are not understood.

There may be other symptoms such as:

- orthostatic intolerance
- fever/chills
- headache
- sore throat
- painful
- tender
- enlarged lymph glands
- muscle and joint aches and pains and weakness
- forgetfulness
- difficulty thinking
- irritability
- anxiety
- reactive depression
- insomnia
- hyper-somnia
- abdominal pain
- bowel dysfunction
- balance disturbances
- dizziness
- palpitations
- breathing difficulties,
- sensitivities to light, noise, vibration, foods and certain chemicals

The impact of the condition depends to some extent on the severity of the case. At the very minimum people with ME/CFS are restricted in their daily activities; in the more severe cases, disability can extend to sufferers being bedridden and in need of significant personal care.

It is common for people suffering these symptoms to become concerned and feel depressed and anxious about not being able to achieve previous levels of involvement in schooling, work, or social activities. Likewise families find it difficult to understand what is happening to their loved ones. In addition to receiving help from health professionals, the ME/CFS Society (SA) Inc. offers information and support to help people manage their lifestyle.

Diagnosis

Unfortunately there is no diagnostic test for ME/CFS. Upon first developing these symptoms, the doctor, based on the patient's medical history, needs to test for diseases that could also produce similar symptoms. If other diseases are excluded, and the symptoms persist beyond 6 months, the diagnosis of ME/CFS can be made.

Treatments

At present there is no cure for ME/CFS. Treatments are directed towards symptom-relief and improving functionality. Unfortunately no one treatment has been demonstrated to benefit a significant proportion of people with ME/CFS; patients may need to try different options, to find what helps them best.

Prevalence

Conservative government estimates suggest 0.2% - 0.7% of people suffer from ME/CFS. In South Australia this equates to 3000 – 10 500 people with ME/CFS.

What's in a Name?

ME, or **Myalgic Encephalomyelitis**, was first used in 1956 to describe the condition. The name suggests muscle pain and inflammation of the brain - originally thought to be the cause of the illness.

In the UK and other parts of the world the term ME is still used although some groups have moved to the term **Myalgic Encephalopathy** which suggests muscle pain and brain dysfunction. This is a far more accurate reflection of the condition, but is by no means a complete description of it.

In 1988 the term **Chronic Fatigue Syndrome (CFS)** was coined by some research groups in the USA. This name 'took off' in some parts of the world and has been used in clinical settings as well as research ones.

Interestingly in the USA, the name **CFIDS** or **Chronic Fatigue Immune Deficiency Syndrome**, was adopted as the clinical term for the condition, based on new theories at the time of the underlying cause of the illness. This is also not considered an accurate description of the disease, but no alternative has yet been found and so it is still used in the USA.

All around the world groups have debated a better name for the condition. Just some of the many suggestions have been: Neuroendocrine Immune Disorder, Polyalgic Asthenia, Nightingale Syndrome, and Ramsay's disorder. Consensus has yet to be achieved on any of these names.

In Australia, most patient groups use the term **ME/CFS**.

NOTE: Some Psychiatrists are attempting to resurrect the term "Neurasthenia" which is a 19C Psychiatric term that was used to describe a syndrome of unexplained mental and physical fatigue of at least three months' duration. In our opinion this is an underhanded attempt to position the illness as a psychiatric not physical condition.

Problems with 'CFS'

It might surprise you that most consumer groups around the world lament the popularisation of the term 'CFS.' In countries such as Australia, where this term has been widely used, it has often generated the perception that the disease is just 'chronic fatigue' when it is actually a multi-



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symptom illness, and fatigue is not always the most disabling or challenging symptom.

It is actually quite arbitrary to select the 'fatigue' symptom. Based on the research definitions, the condition could just as easily be called "Chronic Poor Concentration Syndrome" or "Chronic Unrefreshed Sleep Syndrome". On Chronic Fatigue Syndrome someone has said this is a accurate as calling diabetes "Chronic Thirst Syndrome."

The reason the term 'CFS' has become popular in Australia is, in part, cultural. **Chronic Fatigue Syndrome** is a little easier to understand and explain than **Myalgic Encephalomyelitis**. Consequently **CFS** is often used by the media and by sufferers when referring to the illness. **ME** is a term not really understood in mainstream Australian society, and when its meaning is spelt out, the 'man on the street' appears to be none-the-wiser. We have gravitated to the 'easier' term.

Yet it is important for now that we retain the term ME, because of the issues with 'CFS'. [Interestingly some insurance companies have separate listings for CFS and ME on their databases.] We use the political term ME/CFS but ME & CFS are listed separately in ICD-10.

CFS vs Chronic Fatigue

'Chronic Fatigue' is one of the most commonly reported medical symptoms in humanity – and is caused by a multitude of conditions. ME/CFS is, however, far more than 'chronic fatigue.'

There has been a blurring of distinction between ME/CFS and 'Chronic Fatigue.' And this is really hurting us – causing confusion and retarding the development of our understanding of this condition.

We continue to be appalled by research, government documents and newspaper articles which use these terms interchangeably. In the case of research, so often the title contains the term 'CFS' but the body just says 'Chronic Fatigue.'

The concern with CFS research, is always: 'what definition has been used to determine patients' condition?'. Too often studies reporting to have discovered something about CFS have really been studying people with 'Chronic Fatigue.' We therefore suggest some caution with regard to reported new findings into CFS.

Conclusions on the Name

Until the underlying cause of the condition is known, it is to be expected a number of different names will continue to be used around the world to describe this condition.

GP Recommendations

The CFIDS Association (patient group in the USA) recommends the following for GPs¹:

Individuals with chronic fatigue syndrome (CFS) have special needs practitioners should consider during office

visits. Here are some suggestions to help you provide optimum care:

- Provide a place to lie down. CFS patients may not be able to sit up for long periods of time in the waiting room, your office, or the exam room. They may also be too self-conscious to ask for a place to rest.
- Expect body temperature abnormalities. CFS patients often have low body temperatures and get chilled quickly; they may need a sheet or blanket to be comfortable.
- Draw patients out verbally. The cognitive problems in CFS patients may make it difficult for them to express themselves during the verbal part of the examination. Make questions very specific so that a long response is not required. They may also underreport the type, duration, and severity of symptoms, especially in regard to chronic pain.
- Acknowledge the illness. Saying "you look great" or "you seem much better" can be very discouraging given the fluctuations in symptom severity most patients experience. These types of remarks can be interpreted by patients that the physician does not accept or understand the daily reality of living with CFS.
- Address sensitive issues. It will be difficult for some patients to discuss loss of libido, changes in appetite and weight, and the need for home services, such as help with house cleaning, errands, and bathing. You may need to initiate the conversation.
- Account for medication sensitivity. CFS patients are hypersensitive to medicines, foods, and vaccines. Many also experience unusual side effects. Try prescribing a quarter to a third of the normal initial dosage to start and then increasing slowly as necessary to achieve symptom relief.

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website: www.cfids.org