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# Chronic Fatigue Syndrome (Myalgic Encephalomyelitis)

Myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) is a condition where you have long-term disabling tiredness (fatigue). Most people with also have one or more other symptoms such as muscular pains, joint pains, disturbed sleep patterns, poor concentration or headaches. The cause is not known.

## What is myalgic encephalomyelitis/chronic fatigue syndrome?

Myalgic encephalomyelitis (ME), also referred to as chronic fatigue syndrome (CFS), is a condition that causes marked long-term tiredness (fatigue) and other symptoms which are not caused by any other known medical condition.

- **ME** stands for **myalgic encephalomyelitis**. Myalgic means muscle aches or pains. Encephalomyelitis means inflammation of the brain and spinal cord.
- **CFS** stands for **chronic fatigue syndrome**. Chronic means persistent or long-term.

However, there is controversy about the nature of this condition. There is no test to diagnose the condition. The diagnosis is made in people who have a certain set of symptoms (which can vary in their type and severity). There is even controversy about what to call this condition.

Many people, including some doctors, now think that ME may represent a number of different conditions rather than just one condition. This would explain the considerable variety of different symptoms and the severity of symptoms.

**The rest of this leaflet just uses the term myalgic encephalomyelitis (ME).**

## What are the symptoms of myalgic encephalomyelitis?

The onset of ME symptoms can be fairly sudden (over a few days or so), or more gradual.

### Tiredness (fatigue)

The most common main symptom is persistent tiredness. The tiredness is of new onset. That is, it has not been lifelong but started at a point in time and causes you to limit your activities compared with what you were used to. It is often felt to be both physical and mental tiredness and is said to be overwhelming, or to be like no other type of tiredness. For example:

- It is very different to everyday tiredness (such as after a day's work).
- It is not eased much by rest.
- It is not due to, or like, tiredness following over-exertion.
- It is not due to muscle weakness.
- It is not loss of motivation or pleasure which occurs in people who are depressed.

The tiredness is often made worse by activity. This is called post-exertional malaise. However, the post-exertional malaise usually does not develop until the day following the activity. It then takes several days to improve.

### Other symptoms

In addition to tiredness, one or more of the following symptoms are common (but most people do not have them all). In some people, one of the following symptoms is more dominant than the tiredness and is the main symptom:

- Mental (cognitive) difficulties such as poor concentration, poor short-term memory, reduced attention span, poor memory for recent events, difficulty with planning or organising your thoughts, difficulty finding the right words to say, sometimes feeling disorientated.
- Sleeping difficulties. For example, early waking, being unable to sleep, too much sleep, disrupted sleep/wake patterns.
- Pains - most commonly, muscular pains (myalgia), joint pains and headaches.
- Recurring sore throat, often with tenderness of the nearby lymph glands.
- A range of other symptoms has been reported in some cases. For example, dizziness, a feeling of sickness (nausea) and a 'thumping heart' (palpitations).

Physical or mental exertion will often make your symptoms worse.

## Severity of symptoms

The severity of ME can roughly be divided into three levels:

**Mild cases** - you can care for yourself and can do light domestic tasks, but with difficulty. You are still likely to be able to do a job but may often take days off work. In order to remain in work you are likely to have stopped most leisure and social activities. Weekends or other days off from work are used to rest in order to cope.

**Moderate cases** - you have reduced mobility and are restricted in most activities of daily living. The level of ability and severity of symptoms often varies from time to time (peaks and troughs). You are likely to have stopped work and require rest periods. Sleep at night tends to be poor and disturbed.

**Severe cases** - you are able to carry out only minimal daily tasks such as face washing and cleaning teeth. You are likely to have severe difficulties with some mental processes such as concentrating. You may be wheelchair-dependent for mobility and may be unable to leave your home except on rare occasions. You usually have severe prolonged after effects from effort. You may spend most of your time in bed. You are often unable to tolerate any noise and are generally very sensitive to bright light.

## How is myalgic encephalomyelitis diagnosed?

There is no test that proves that you have ME. A doctor will usually diagnose ME based on your symptoms. Some tests are usually done to rule out other causes of your tiredness (fatigue) or other symptoms. For example, blood tests may be done to rule out [anaemia](#), an [underactive thyroid gland](#), liver problems and kidney problems. All these tests are normal in people with ME.

## What causes myalgic encephalomyelitis?

The cause of ME is not known. There are various theories but none has been proved. A popular theory is that a viral infection may trigger the condition. It is well known that tiredness (fatigue) is a symptom that can persist for a short time following certain viral infections. For example, infection with the [glandular fever](#) virus or the [influenza virus](#) can cause fatigue for several weeks after other symptoms have gone. However, most people recover within a few weeks from the tiredness that follows known viral infections.

Even if a viral infection is a trigger of ME, it is not clear why symptoms persist when there is no evidence of persisting infection. Also, the symptoms of many people with ME do not start with a viral infection.

Factors that are thought to contribute to some people developing ME include:

- Inherited genetic susceptibility (it is more common in some families).
- Viral infections such as glandular fever.
- Exhaustion and mental stress.
- Depression.
- A traumatic event such as bereavement, divorce or redundancy.

It is hoped that research will clarify the cause (or causes) of ME in the future.

## Who develops myalgic encephalomyelitis?

ME can affect anyone. It is estimated that ME affects about 1 in 300 people in the UK, possibly more. It is about three times as common in women as in men. The most common age for it to develop is in the early twenties to mid-forties. In children the most common age for it to develop is 13-15 years but it can develop at an earlier age.

## What is the treatment for myalgic encephalomyelitis?

There is no known cure for ME, although treatment may help to ease symptoms. You are likely to be referred to a specialist who will be able to offer you support and treatment. Treatments that may be considered include the following.

### Management of your symptoms

[Painkillers](#) may help if muscle or joint pains are troublesome symptoms. Eating little and often may help any feeling of sickness (nausea). Specific diets have not been shown to be beneficial.

Depression can occur in people with ME - as it can in many other persistent (chronic) diseases such as heart or lung disease. Depression can make many symptoms worse. [Antidepressants](#) may be prescribed if depression develops.

### Management of your quality of life and function

#### Managing your sleep

It is likely you will be given advice about your sleep. Any changes to your sleep pattern (for example, having too little, or even too much, sleep) may actually make your tiredness (fatigue) worse. This includes sleeping in the daytime, which should ideally be avoided. Any changes to your sleep pattern should be done gradually.

## Managing rest

Setting aside times to rest (rather than actual sleep) is very beneficial. You should introduce rest periods into your daily routine. These should ideally be limited to 30 minutes at a time and be a period of relaxation.

## Relaxation

Relaxation can help to improve pain, sleep problems and any stress or anxiety you may have. There are various relaxation techniques (such as guided visualisation or breathing techniques) which you may find useful when they are built into your rest periods.

## Pacing

This means balancing periods of activity and rest and becoming aware of which activities demand most from you. You should aim to stop activities before you feel the impact so that you have enough energy in reserve. Doing too much on a good day may make you feel the impact later. It can take time to change your usual activities but pacing is very important in managing your condition in the long term.

## Diet

It is very important that you have a well-balanced diet. You should try to avoid any foods and drinks to which you are sensitive. Eating small, regular meals which contain some starchy foods is often beneficial.

## Other treatments

Graded exercise therapy and cognitive behavioural therapy have been recommended by the National Institute for Health and Care Excellence (NICE) guidelines, but may not be of any benefit or may even make symptoms worse. The NICE guidelines are currently being reviewed.

## General support

Depending on the severity of illness, other support may be needed - for example, carers, nursing support, equipment and adaptations to the home to help overcome disability.

If you are employed, your doctor will be able to advise you about whether you should take time off work. And, if you take time off work, when you may be ready to go back to work. It may be that you need to work doing slightly different hours or even with different duties. If you have an occupational health department at work, they are likely to be involved with you also regarding work and going back to work if you take time off.

## Complementary treatments

As there is only limited success with conventional treatments, it is understandable that people turn to complementary practitioners. Many people with ME find various therapies helpful. However, there is not enough research evidence to support the use of complementary therapies for the treatment of ME.

There is also insufficient evidence to recommend the use of supplements (for example, vitamins).

## Managing setbacks (relapses)

It can be common to have setbacks when symptoms become worse for a while. These can have various triggers - for example, poor sleep, infection or stress.

Your doctor may discuss with you strategies which may help during a setback. These may include relaxation techniques, talking with your family, and finding the right balance between activity and rest, if possible. However, it may be necessary for you to reduce or even stop some of your activities and increase the amount of rest you have during a setback.

Following a setback you should usually be able gradually to return to your previous activity level.

## What is the outlook (prognosis)?

In most cases, ME has a fluctuating course. There may be times when symptoms are not too bad and times when symptoms flare up and become worse (a setback). The outcome is very variable and there is currently no effective method for predicting how the illness will progress or whether it will improve or resolve for any individual person.

## Further reading & references

- [Chronic fatigue syndrome/Myalgic encephalomyelitis \(or encephalopathy\) diagnosis and management](#); NICE Clinical Guideline (August 2007)
- [Newly diagnosed with ME/CFS - information and advice for you and your GP](#); Action for ME
- [White PD, Goldsmith KA, Johnson AL, et al](#); Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *Lancet*. 2011 Mar 5;377(9768):823-36. Epub 2011 Feb 18.
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- [Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#); Board on the Health of Select Populations; Institute of Medicine; Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. February 2015.
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