

CFS/ME

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis

CFS/ME is a condition where you have long-term disabling tiredness (fatigue). Most people with CFS/ME also have one or more other symptoms such as muscular pains, joint pains, disturbed sleep patterns, poor concentration, headaches, etc. The cause is not known. Treatments that may help in some cases (but not all) include a programme of graded exercise, cognitive behaviour therapy, and 'pacing'.

What is CFS/ME?

CFS/ME is a condition that causes marked long-term fatigue and other symptoms which are not caused by any other known medical condition.

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

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.

- The term CFS is often used by doctors. This is because the main symptom is often fatigue and the condition is chronic (persistent). Also, there is no evidence of inflammation in the brain or spinal cord which is implied by the term encephalomyelitis.
- The term ME is the preferred term by many people with the condition. Some people with this condition feel that the term 'fatigue' is an everyday word which does not reflect the different and severe type of fatigue that they have. Also, although fatigue to some extent occurs in most cases, it may not be the main or only symptom.
- Some people believe that there are two separate conditions - CFS and ME. Other people believe that the two conditions are the same - but symptoms can vary.

Until these issues are resolved, many people now use the 'umbrella' term of CFS/ME.

What causes CFS/ME?

The cause of CFS/ME is not known. There are various theories - but none are proved. A popular theory is that a virus infection may trigger the condition. It is well known that fatigue is a symptom that can persist for a short time after having certain virus 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 fatigue that follows known viral infections. Even if a viral infection is a trigger of CFS/ME, it is not clear why symptoms persist when there is no evidence of persisting infection. Also, the symptoms of many people with CFS/ME do not start with a viral infection.

There are various possibilities. For example:

- CFS/ME may not be one or even two conditions. It may include several conditions each with a different cause. Each of the conditions may cause similar symptoms, but with present knowledge cannot be distinguished, or:
- CFS/ME may be one condition, but which may be triggered by more than one cause, or:
- CFS/ME may be one condition, with one cause.

Hopefully, research will clarify the cause of CFS/ME in the future.

Who gets CFS/ME?

CFS/ME can affect anyone. The precise number of people affected is not known. It is estimated that CFS/ME affects about 1 in 300 people in the UK, possibly more. It is about twice as common in women than in men. The commonest age it develops is early twenties to mid-forties. In children the commonest age it develops is 13-15, but it can develop at an earlier age.

How is CFS/ME diagnosed?

There is no test that proves that you have CFS/ME. A doctor will usually diagnose CFS/ME based on the symptoms. Some tests may be done to rule out other causes of fatigue or other symptoms that develop. For example, blood tests may be done to rule out anaemia, an underactive thyroid gland, liver and kidney problems, etc. All the tests are normal in people with CFS/ME.

The strict medical definition of CFS/ME states that symptoms should have lasted for at least six months. However, the diagnosis is often made sooner than this if other causes of fatigue and other symptoms have been ruled out.

What are the symptoms of CFS/ME?

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

Fatigue

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

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

The fatigue is often made worse by activity. This is called 'post-exertional malaise'. However, the post-exertional malaise may not develop for several hours or more following the activity. It may even develop on the following day.

Other symptoms

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

- Mental ('cognitive') difficulties such poor concentration, reduced attention span, poor memory for recent events, difficulty to plan or organise your thoughts, difficulty 'finding the right words' to say, sometimes feeling disorientated.
- Sleeping difficulties. For example, early waking, 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.
- Intolerances and sensitivities to foods, alcohol, noise and bright light.
- Gut symptoms similar to those that occur in 'irritable bowel syndrome'. For example, excess, wind, bloating, alternating diarrhoea and constipation, abdominal pains, nausea (feeling sick).
- A range of other symptoms have been reported in some cases such as dizziness, excess sweating, difficulties with balance, and disordered temperature control of the body.

The severity of symptoms

The severity of CFS/ME can roughly be divided into four 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, often sleeping in the afternoon for one or two hours. Night-time sleep 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, and usually have severe prolonged after-effects from effort.
- Very severe - you will be unable to mobilise or carry out any daily tasks for yourself and are in bed for the majority of the time. You are often unable to tolerate any noise, and are generally very sensitive to bright light.

Most cases are mild or moderate but up to 1 in 4 cases are severe or very severe.

What is the treatment for CFS/ME?

There is no known cure for CFS/ME although treatment may help to ease symptoms. Three commonly tried treatments which seem to help in some cases are graded exercise, cognitive behaviour therapy, and pacing.

Graded exercise

Graded exercise means a gradual, progressive increase in aerobic activities such as walking or swimming. It is based on the theory that a factor that helps to maintain the illness is inactivity, with subsequent physical 'deconditioning'. A very gradual increase in the level of exercise is thought to help to reverse this process. Some research studies showed that, on average, people with CFS/ME improved with a structured programme of graded exercise compared to those who did not have this treatment.

However, the research studies only included people who were able to attend the course of treatment. That is, those people only mildly or moderately affected. It is not known whether this treatment is useful for everyone with CFS/ME, especially those with severe or very severe CFS/ME. Some people with CFS/ME say that graded exercise has made them worse.

Therefore, it seems that graded exercise is an option to consider. But, only after a full discussion with your doctor, and with agreement to the rate at which the level of exercise is increased over time. It should be tailored to suit each individual case. Ideally, it should be supervised by a physiotherapist or occupational therapist who is used to treating people with CFS/ME.

Cognitive behaviour therapy (CBT)

Cognitive therapy is based on the idea that certain ways of thinking can 'fuel' certain health problems. Behaviour therapy aims to change any behaviours that are harmful or not helpful. CBT is a combination of cognitive and behaviour therapy. The use of CBT does not imply that the cause of an illness is psychological. CBT can help various physical and mental health problems.

CBT does not aim to 'cure' the condition but helps to improve symptoms, coping strategies, and day-to-day functioning. For people with CFS/ME the core components of CBT would normally include: energy/activity management, establishment of a sleep routine, goal setting, and psychological support. Research studies looking at CBT for CFS/ME found a positive overall effect of the treatment. The studies showed that most people who completed a course of CBT improved in both function and fatigue.

One problem is that CBT is not widely available in the UK on the NHS. If it is available in your area, it is certainly worth considering in addition to any other treatment. Also, like graded exercise, the research studies did not include those who were severely affected with CFS/ME and it is not known if it will help in this situation. Also, some people who start a course of CBT (for any condition) drop out of the course for one reason or another as CBT does not suit everybody.

Pacing

Pacing is a strategy in which people with CFS/ME are encouraged to achieve a balance between rest and activity. This usually involves living within the limitations caused by the illness, but having some limited types of activity alternating with periods of rest. The aim is to prevent a 'vicious circle' of overactivity and setbacks ('boom and bust'), while setting realistic goals for increasing activity when appropriate. The theory is that if you use your energy wisely, your limited energy may increase gradually.

Again, there is controversy over pacing as a specific 'therapy' as there is little research evidence that has shown how effective it is.

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.

Treating associated symptoms

Depression is quite common in people with CFS/ME (as it is with many other chronic diseases). Depression can make many symptoms worse. Antidepressants may be prescribed if depression develops and may help to ease some of the symptoms (for example, pain, poor sleep). Painkillers may help if muscle or joint pains are troublesome symptoms.

Other treatments

As there is only limited success with conventional treatments it is understandable that people turn to complimentary practitioners. Many people with CFS/ME find various therapies helpful. However, there is little research evidence to say how effective complementary therapies are for CFS/ME. Also, there is some concern that some therapists cause confusing or misleading health beliefs, recommend unnecessary tests, and may prescribe treatments that have no scientific proof of success (and in some cases can be harmful). In particular, beware of anyone who claims to have a 'cure' for CFS/ME - especially when it costs a lot of money.

What is the outlook (prognosis) for people with CFS/ME?

In most cases, the condition has a fluctuating course. There may be times when symptoms are not too bad, and times when symptoms flare up and become worse. The long-term outlook is variable.

- Most people with CFS/ME will show some improvement over time, especially with treatment. Some people recover in less than two years, while others remain ill for many years. However, health and functioning rarely return completely to previous levels. Most people who recover stabilise at a lower level of functioning than that before their illness.
- In some cases the condition is severe and/or persists for many years. Those who have been affected for several years seem less likely to recover.

Further information and support

ME Association

4 Top Angel, Buckingham Industrial Park, Buckingham, MK18 1TH
Tel: 0870 444 1835 Web: www.meassociation.org.uk

Action for ME

PO Box 1302, Wells, Somerset, BA5 1YE
Tel: 01749 670799 Web: www.afme.org.uk

Association of Young People with ME (AYME)

P O Box 605, Milton Keynes, MK2 2XD

Tel: 08451 232389 Web: www.ayme.org.uk

Tymes Trust (The Young ME Sufferers Trust)

PO Box 4347, Stock, Ingatestone, CM4 9TE

Tel:01245 401080 Web: www.tymestrust.org

A national UK service for children and young people with ME and their families.

The 25% ME Group (Support for people who have the severe form of CFS/ME)

4 Douglas Court, Beach Road, Barassie, Troon, Ayrshire, KA10 6SQ

Web: www.25megroup.org

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Comprehensive patient resources are available at www.patient.co.uk