BMJ Best Practice

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Myalgic encephalomyelitis (chronic fatigue syndrome)

Myalgic encephalomyelitis, or chronic fatigue syndrome (sometimes called ME/CFS) is a frustrating and distressing illness that affects people of all ages. No one knows what causes it and there is no cure. But there are things you can try that may help you feel better.

What happens in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)?

Many of us feel tired from time to time, especially if we are under stress with work or personal problems, or if we just have busy lives.

But ME/CFS is different. People with ME/CFS may feel exhausted and unwell after normal daily activities such as walking or concentrating on a task. It stops them getting on with their normal activities and enjoying life.

We don’t know why ME/CFS happens. Some people find their symptoms start after an illness caused by a bacterial or viral infection. And people with post-COVID-19 syndrome (long covid) have symptoms similar to ME/CFS. This suggests that one of the causes of ME/CFS could be something going wrong in the way your body responds to infection.

It is thought that other things may trigger ME/CFS in some people, such as physical trauma (for example, a road traffic accident or major surgery) or something passed down in your genes. But it can come on gradually for no obvious reason.

ME/CFS can last from a few months to many years, although the symptoms may come and go during that time. It can affect adults and children.

What are the symptoms?

A main symptom of ME/CFS is feeling completely exhausted, and often unwell, after even a small amount of activity that doesn’t significantly improve when you rest. This differs from other chronic (long-term) conditions that also involve fatigue. You may also:

- Feel tired and unrefreshed after sleeping
- Have trouble sleeping or concentrating
- Have trouble thinking, with your memory, with finding the right word or difficulty multitasking
- Have muscle or joint aches and pains
- Have headaches
- Have a sore throat
- Feel dizzy, lightheaded or sick
- Feel like your heart is beating fast.

If you are worried that you or your child may have ME/CFS, see your doctor. There's no simple test for CFS. But your doctor will ask you some questions about your general health and your life, and will check whether your symptoms may be caused by anything else. For example, you might have blood tests to check for other causes.

Other conditions that can cause tiredness include:

- A long-lasting infection
- Anaemia (usually caused by a lack of iron)
- Problems with your thyroid gland
- Diabetes
- Depression
- Anorexia or bulimia
- Alcohol or drug abuse
- Ongoing stress.

Tiredness can also be caused by pregnancy or other hormonal changes, such as the menopause.

It is important for your doctor to be sure that no other problems are causing your symptoms. If your symptoms are caused by something other than ME/CFS it's important that you get the right treatment. So you should tell your doctor about any other health problems or concerns you have.

If you have had symptoms that have lasted for at least 3 months without any other cause being found, your doctors may say you have ME/CFS. In some countries, adults may need to have had symptoms lasting for at least 6 months for the diagnosis to be confirmed.

What treatments work?

We don't know what causes ME/CFS so it's hard to know how to treat it. There is no cure. The aim of treatment is to reduce the symptoms and help you live as normal a life as possible.

Treatment without medicines

Multidisciplinary support means working with several different types of healthcare professionals as well as your primary care doctor, for example physiotherapists and occupational therapists. The types of treatments and specialists you need will depend on your own symptoms and needs.

Pacing

Pacing, sometimes known as ‘energy management’, aims to find the right balance, for you, between rest and the activities of everyday life, including exercise. The idea is that if you have less energy but use it carefully, your energy will gradually increase. Pacing involves:

- Learning how to check your energy and activity levels so that you can change how much you are doing as needed
- Dividing tasks and activities up into 'chunks' that are easier to manage, instead of trying to do too much at one time
- Taking control of your personal energy and activity levels rather than following other people’s advice if it doesn’t feel right to you.

If you have ME/CFS you will need support from your healthcare team to help you manage how much you can do each day and to avoid overdoing it. Your symptoms may come and go, so you'll need to plan each day's activities carefully. Try to save your energy for the things that are most important to you. You'll need to plan rest as needed.

Cognitive behaviour therapy (CBT)

CBT is a type of psychotherapy or 'talking treatment' that you might be offered; it may or may not be right for you. It aims to help encourage positive thoughts and behaviours instead of negative ones. This type of therapy may be particularly useful in helping you deal with your diagnosis and help improve your quality of life. It may also help if you have any mental health problems such as depression or anxiety alongside your ME/CFS. It may also help if you have trouble sleeping at night. There is some evidence that CBT can help people feel less tired and more positive. CBT may also help children with ME/CFS attend school more regularly.

When you have CBT you meet with a trained therapist for several sessions. There's no evidence that CBT causes any harmful side effects.

Family CBT sessions can help other people in your life learn about ME/CFS and how it affects you. This can help them support you better.

Mindfulness and other types of therapy

You might have heard about **mindfulness** being helpful for other conditions, such as stress. It aims to help you focus as calmly as possible on your present situation (in this case your ME/CFS). This can help you accept how you feel about your condition and may help manage your symptoms. The hope is that once you have accepted it you can begin to make clearer decisions based on what's best for your recovery. It can also improve your mood.

Other types of therapy which may be useful include **relaxation therapy**, which can help with things like getting regular sleep.

Referral to an occupational therapist or physiotherapist

If your ME/CFS causes you problems getting out and about, an occupational therapist can help you with aids and equipment that might help. For example, a ramp or lift at home, or a disability parking permit may be helpful.

There's some evidence that an **exercise** programme can help some people. But any exercise programme needs to be supported by professionals, such as a physiotherapist with expertise in ME/CFS. A programme needs to be carefully matched to what you are able to do and what feels comfortable.

It should also take into account day-to-day changes in your symptoms. For example, if you feel more tired and unwell than usual, it might make sense to rest rather than to do your usual amount of exercise.

If you're planning your exercise programme with a doctor or therapist, you should not be expected to do anything you don't feel capable of doing. Doing too much exercise too soon is likely to make you feel worse.

This is especially true if you have been unwell for a long time and your bones and muscles are no longer used to exercise. You will need to take a very gentle approach to exercise.

Treatment with medicines

There are no medicines that can treat the fatigue caused by ME/CFS. But some people with the condition take medicines to treat some of the other symptoms.

As with other chronic conditions, some people with ME/CFS develop symptoms of depression. Some people are prescribed antidepressant medicines to help with this.

Some people are also prescribed medicines to help with other conditions, such as disturbed sleep, pain, migraines, or irritable bowel syndrome. These conditions occur more often in people with ME/CFS.

What will happen to me?

ME/CFS can last for years. It can make you feel very ill and miserable, and can get in the way of your family, social, and work or school life.

The good news is that most **children** recover completely.

Recovery is less certain for **adults**. Most people tend to improve over time, but few recover completely. For example, even if you feel better most of the time, you might still have times where you feel very tired.

You may find it more difficult to recover if you are older or if your symptoms are severe. It may be harder if you also have a mental health problem, such as depression.

Where to get more help

Talking to other people with the same condition is very important when you are living with and recovering from ME/CFS. It can help you learn from their experiences and feel as though you are not alone. And there are many charities and support groups that offer help. Your doctor may be able to suggest where to get help where you live. Or you can search online.

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