

Patient information from BMJ

Last published: Apr 19, 2021

Chronic fatigue syndrome

Chronic fatigue syndrome 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 chronic fatigue syndrome?

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 chronic fatigue syndrome (CFS for short) is different. People with CFS feel exhausted and weak most of the time. It stops them getting on with their normal activities and enjoying life.

It is thought that the lack of energy when you have CFS may be caused by problems with your immune system or with the way energy is produced in your cells.

CFS is sometimes called myalgic encephalomyelitis (ME for short), or CFS/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 CFS is feeling completely exhausted, and often unwell, after even a small amount of activity. 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 muscle aches
- have headaches
- have a sore throat.

Doctors won't say that you have CFS until you have had the symptoms for 6 months (for adults). For children, the diagnosis may be made after 3 months.

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Sometimes CFS starts after another illness, such as a bad cold that seems to linger for longer than it should. And some people find it starts during a time of stress. But it can also come on gradually for no obvious reason.

If you are worried that you or your child may have 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 fatigue may be caused by anything else. For example, you might have blood tests to check for an infection.

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, and
- 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 CFS it's important that you get the right treatment. So you should tell your doctor about any other health problems you have and about any other prescription and over-the-counter medicines and supplements you are taking.

What treatments work?

We don't know what causes CFS so it's hard to know how to treat it, and there is no cure. The aim of treatment is to ease the symptoms and help people live as normal a life as possible.

Treatment without medicines

Multidisciplinary rehabilitation sounds complicated but the idea is quite simple. It's an approach that aims to combine the benefits of several different treatments to help your recovery as much as possible. The programme includes sessions with several types of therapist, including a physiotherapist and an occupational therapist.

It includes elements of:

- a form of psychotherapy (a 'talking treatment') called cognitive behaviour therapy (CBT)
- pacing (finding a balance between activity and rest)
- relaxation therapy, which can help with things like getting regular sleep
- therapy to help you deal with social situations

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- mindfulness.

You might have heard of or read about mindfulness in connection with other conditions, such as stress. It aims to help you focus as calmly as possible on your present situation (in this case your CFS) and accept it. The hope is that once you have accepted it you can begin to make useful decisions based on what's best for your recovery.

Cognitive behaviour therapy (CBT) is a form of psychotherapy or 'talking treatment'. The idea is that the therapy will help you to encourage positive thoughts and behaviours over negative ones. There is some evidence that it can help people with CFS feel less tired and more positive. CBT may also help children with 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.

There's some evidence that a **graded aerobic exercise** programme can help some people with mild fatigue feel less tired. It means starting gently and building up your activity levels.

The important thing about exercise programmes is that they are tailored to each person's needs and abilities. 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 than ever.

This is especially true if you have been immobile for a long time and your bones and muscles are no longer used to exercise. You will need to take a very cautious and gentle approach to exercise. Do only what you feel comfortable doing and stop when you feel you need to stop.

Pacing aims to find the right balance, for you, between rest and the activities of everyday life, including exercise. The idea is that if you use what limited energy you have carefully, your energy will gradually increase. Pacing involves:

- checking your energy and activity levels so that you can adjust your activity up or down
- dividing tasks and activities up into achievable 'chunks' rather than trying to do too much at one time
- taking control of decisions about your personal energy and activity levels rather than following expert advice to the letter.

If you have CFS you will need support from your healthcare team to help you try to increase how much you can do each day. Your symptoms may come and go, so you'll need to plan each day's activities carefully and to try to save your energy for the things that are most important to you. You'll need to schedule rest as needed and to work with your team to try to help you to sleep better at night.

Treatment with medicines

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

As with other chronic conditions, about 4 in 10 people with CFS develop symptoms of depression. Some people with CFS are prescribed antidepressants.

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Some people are also prescribed medications to help with conditions that often occur in people with CFS, such as disturbed sleep, pain, migraine, or irritable bowel syndrome.

What will happen to me?

CFS can last for years. And, although it's not medically dangerous, it can make you feel very ill and miserable, and can interfere with your family, social, and work life.

The good news is that most children recover completely. The outlook is less certain for adults. Although a lot of people do gradually feel better, most still have periods of feeling very tired. You may find it more difficult to recover if you are older, if your symptoms are severe, or if you also have a mental health problem, such as depression.

Where to get more help

Talking to other people with the condition, learning from their experiences, and feeling as though you are not alone, can be crucial in living with and recovering from CFS. And there are many charities and support groups that offer help.

For example, in the UK, the ME association (<http://www.meassociation.org.uk/>) and Action for ME (<https://www.actionforme.org.uk/>) offer information and local support to people with CFS. Your doctor may be able to suggest where to get help where you live. Or you can search online.

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