

ME what is it and how is it treated?

Around 1 in 250 people have been diagnosed with ME in the UK alone. Sometimes more than one family member is affected suggesting that genes have a role to play. It affects men and women of all ages, ethnic groups and social status and is commonly seen in teenagers and children who are often affected very severely.

So what is ME?

Myalgic Encephalomyelitis, or ME, is a neurological illness characterised by extreme fatigue, poor concentration and short term memory and muscle pains. The symptom list looks more like a shopping list which explains why doctors also call it CFS: Chronic Fatigue Syndrome.

What are the symptoms?

Everyone with ME is different: you don't have to have all of the symptoms to be diagnosed with ME and the ones you do have can vary in severity from day to day and between individuals.

You may have:

- Overwhelming and persistent fatigue that is not improved by rest and sleep. The fatigue can be delayed by up to 48 hours.
- Malaise – feeling as though you've had a severe bout of flu. Sometimes people have sore throats and swollen glands too.
- Nausea – if you have it severely you can retch or vomit, particularly on an empty stomach.
- Poor temperature control – you might feel very hot, faint and sweaty when you are doing a mild activity such as standing or walking and you might feel extremely cold when you are sitting or lying. Some people find warm climates intolerable as they feel so faint and cannot cool down and are miserable in cold climates because they feel continually chilled.

- Dizziness, including trouble with keeping your balance.
- Pain – in muscles and joints which is made worse by activity. Muscles may twitch. Some people's hands and feet are permanently painful – and cold - and they may experience burning sensations or pins and needles.
- Headaches and migraines.
- Sleep problems – you may want to sleep in the day and are unable to sleep at night or you may have trouble sleeping altogether despite feeling exhausted. And when you do sleep, it is unrefreshing and often of poor quality – you are easily disturbed and wake often.
- Concentration and short-term memory are often poor – this has been commonly described as 'brain fog'. You might also have trouble finding the right words, remembering people's names and have difficulty explaining things.
- Diarrhoea and constipation – or a combination of the two – are common. Irritable Bowel Syndrome (IBS) is also often found in people with ME.
- Intolerance to some medication and foods – and alcohol.
- Increased sensitivity to touch, light, smells and noise.
- Increased susceptibility to infections – due to an impaired immune system.

How is it Diagnosed?

At the moment there is no simple diagnostic test for ME. Often a diagnosis is made by ruling out other possibilities. This means that you can wait from six months to several years for a diagnosis – not all doctors know what they are looking for. So you may need to suggest that they consider ME if you have fatigue that prevents you from working or

living an ordinary life and it persists for more than a few months.

The sooner you are given a confirmed diagnosis, the better your chances of recovery because you will be given advice in managing your illness. You can also be given medication to ease some of your symptoms.

Advice

- Find out what state benefits, if any, you are entitled to – including Incapacity Benefit and Disability Living Allowance. Seek advice from one of the ME organisations (see below) before you fill in any application forms.
- Plan for busy times. For example, if you know you have a family commitment or an appointment, take extra rest before you go and allow for extra rest when you get back. Don't have two busy days in a row.
- Write things down on Post It stickers to help you remember what you need to do.
- Try to accept your physical limitations and find new ways of enjoying yourself. For example, if you are too tired to read or it is too painful to hold a book, join a listening book library – you will need a letter from your doctor to show you have trouble 'reading in the normal way'.
- Avoid multi-tasking as it can be more tiring than doing things separately and resting in between.
- Value friends and family; they will help sustain you through the difficult times ahead.

What causes ME?

There is no single cause of ME. Some people get ME after having an infection – usually a viral one such as flu or glandular fever. Some

people have been exposed to chemicals such as organophosphates, or have reacted badly to a vaccination or have had ME start following an accident, a pregnancy or an operation. For many people there is no obvious cause.

How is it treated?

There is no cure for ME; the condition can only be managed. Doctors can prescribe medication to control pain, help with sleep and relieve low mood and anxiety – but they need to start you on sub-clinical doses and gradually build up to a normal dose as you may be sensitive to the drug. Many patients with ME become depressed and anxious because their life is radically changed and they suffer a multitude of symptoms that can go on for years, decades even.

Some antidepressants, known as SSRIs, have been found to be helpful in treating ME whether or not a patient is depressed as well because the brain is lacking in certain chemicals to allow it to function properly. These drugs can help replace those chemicals and so improve fatigue and other symptoms. However, not everyone can tolerate SSRIs.

In the initial stage of the illness, you may need to be sleeping and resting most of the time but later there should be a small increase in what you can do. It is important not to overdo things on a good day and then have to spend a week recovering – long periods of bed rest can lead to muscle wasting and weakening. An important part of managing ME is pacing – alternating rest with periods of activity. It can take some time to learn how to do this effectively; one of the hardest things is stopping doing something before you get too tired. But with effective management, you will be able to do a little more. Over time, you may be able to increase your levels of activity to lead more of a normal life.

Some doctors refer patients for Graded Exercise Therapy (GET) but there has been controversy over this treatment. When therapists without experience of working with ME give a patient GET the patients can be made worse. Cognitive behavioural therapy (CBT) is another frequently given treatment; it helps you adjust to living with ME and to making the most of the life that you do have within the bounds of the illness.

What else can I do?

Many people with ME have made lasting changes to their diet such as avoiding wheat, sugar and caffeine, eating organic food and taking supplements, but these things do not help everyone. You will need to seek advice from your doctor and a nutritional therapist: be wary of strange diets that cut out too many valuable sources of calories, vitamins and minerals.

Learning to relax and regularly following a relaxation recording can be helpful to reduce stress as this worsens ME. It can also help revitalise a tired body and aid sleep.

What else should I know?

Although ME is a serious debilitating illness that can leave severely affected people bed-bound and dependent on tube feeding, it often does not get people the sympathy and understanding they deserve. Some people may suggest you are lazy or are just not trying – they manage to get to work when they are ‘under the weather’ so why can’t you?

Some people say things like, ‘I don’t believe in ME’ or, ‘That’s Yuppie flu isn’t it?’ and belittle the devastating effect it has on your, and your family’s, life. If you meet with resistance, become informed and have information ready to show people that you are genuinely ill. It is a double blow when you are not believed about how bad you feel.

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