

How should I deal with a person with ME/CFS?

The most important thing to remember, is that ME sufferers get very tired, and it may be disastrous for them not to rest when they need to, and for as long as they need to. Also, 'normal' activities like conversation, which require very little energy from a healthy person, may be very exhausting for someone with ME. If an ME sufferer tells you they have to rest, or they cannot carry on talking to you, or they want you to leave, respect their need. It may seem selfish, but be assured – it is absolutely necessary.

Similarly, if a sufferer tells you they are not physically capable of doing something (e.g. walking to the corner shop) - Believe them. What they may mean is that they *might* be able to do whatever it is, but know that they will suffer for it afterwards.

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Sometimes, an ME sufferer may appear not to be taking in what you are saying to them. These problems of concentration and memory are symptoms of the illness, and will vary according to how ill the person is feeling, and how exhausted they are. Slow down your conversation, and if necessary say or explain things to the sufferer a second time, without being patronising.

What can I do to help?

The best you can do is be there for the person you care for. Give plenty of TLC, but most important — be patient!



“The Voice for ME
in the Northern Region”

Improving the quality of life
for people with ME/CFS
their families and carers

A Guide To ME

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What is ME?

ME is an illness and stands for Myalgic Encephalopathy – which is a bit of a mouthful but basically means muscle (myalgic) and head (encephalic) symptoms. ME is also known as Chronic Fatigue Syndrome (CFS), and also Post-Viral Fatigue Syndrome (PVFS) because it often follows on from a viral infection. Doctors prefer to call it CFS, patients ME, so to please both sides we call it ME/CFS.

How does ME/CFS start?

Often it will start after an ordinary viral infection – flu, chicken-pox, glandular fever. It is possible for an apparently healthy person to come down with a viral infection, and develop full-blown ME immediately. In other cases, there may be no obvious viral 'trigger' at all, and the person may slide into the illness over a period of months or even years. Older people tend to develop ME in this way.

What causes ME/CFS?

It is not known exactly what causes ME but research has revealed a number of abnormalities in ME sufferers. Findings include evidence of persisting viral infection, abnormalities in skeletal and cardiac muscle structure and function, and evidence of damage to nervous tissue.

What are the symptoms?

As its name suggests, ME mainly affects the muscles and the head: muscle symptoms include severe fatigue on exercise, muscle pain and spasms. It's important to appreciate that the kind of fatigue experienced by many ME sufferers is quite different from the straightforward 'tiredness' most normal people experience. ME sufferers have likened the fatigue to being 'totally drained' of energy and unlike many other illnesses, exercise may make things worse. Any physical activity – even walking up or down stairs – may cause pain and discomfort, and even cause a

major relapse. Sometimes, you will see ME sufferers apparently able to do quite normal things physically, yet complaining of terrible fatigue and muscle problems.

What you haven't seen is the price they pay afterwards for their physical exertion – perhaps days in bed recovering. Some sufferers have learnt how to 'save up' energy to enable them to do things, know exactly how much they can do – and what price they may have to pay afterwards. It is as though their muscles have a limited 'energy supply'. When this runs out, the muscles stop functioning and need time to 'recharge'.

The head symptoms experienced by ME sufferers include: headaches, dizziness, 'swimmy' feelings and perhaps most difficult of all to handle, loss of concentration and short-term memory. ME sufferers will often forget things you have just told them, and will find it hard to take in new information – especially if it's complicated. These problems will tend to be worse when fatigued and mental exertion, as well as physical, may be exhausting for people with ME.

These are not the only symptoms experienced in ME. Sufferers will often feel 'all over', and experience many flu-like symptoms: nausea, shivering, fever and aching joints. They may over-react to heat and cold. Digestive problems are common, such as constipation, diarrhoea, gas, bloating and pain.

Other Common Symptoms

Many people have allergies or intolerances to food or substances in the environment, you may come across people who are on restricted diets. Similarly, some people with ME find that things like exhaust fumes, perfume or ordinary household chemicals affect them very badly.

Is this a 'New' disease?

ME has been around – under different names – for at least a century. It was probably seen before then, but in far fewer people. So it isn't a 'new' disease – but rather a *newly recognised* disease. There are around 250,000 people with this illness so it is fairly common.

How many people have ME/CFS?

Population prevalence is 0.4% (250,000 nationally – 12,000 in the Northern region). It can occur at any age, is twice as common in women, it affects all social classes and ethnic groups.

What kind of people have ME/CFS?

ME strikes people of all ages (including very young children and very old people), and all social classes. There do seem to be more women than men with ME, and the reasons for this are not known.

Most of them had an active, enjoyable lifestyle before becoming ill, and would like nothing more than to return to it.

How long does it last?

Many people experience a period of what is known as 'post-viral debility' – after having flu for instance. This post-viral fatigue may feature many of the symptoms of ME, but rarely lasts more than a few weeks.

In a minority of cases, it may last longer, and it is generally agreed that if it lasts longer than four months, and the symptoms correspond, then it may be considered to be ME.

How do you forecast the outcome?

Prognosis is extremely variable. Early intervention and positive clinical input is likely to improve the outcome.

What specialist help is there for ME/CFS?

Some local specialist teams are available and referral can be made for benefits assessment, therapy services, or to confirm a diagnosis. Guidelines recommend referral at 4 months since on-set of symptoms. Diagnosis should be considered after 4-6 weeks of onset of abnormal fatigue (please note that seeing a GP may come significantly later than symptom onset).

How do people get a referral?

Referrals are made through your GP following strict referral criteria.

All GPs have received information about the clinical teams, but should anyone have any problems, contact ME North East.

How ill is a person with ME/CFS?

Like any other illness, ME affects everyone differently, and some are more affected than others.

The most severely affected sufferers are completely bedridden, in constant pain and unable to attend to normal bodily functions.

Others may be in wheelchairs much of the time to allow them to get out and about and do normal things like shopping and visiting friends.

Those who are quite mildly affected may still be working or going to school full time – and appear OK—but may be having to rest every evening and weekend just to maintain their energy levels at work or school.

Even quite severely affected sufferers may look healthy – be assured, they're not. The same applies in other illnesses such as Multiple Sclerosis.

ME is a very variable illness – it does tend to following a course of 'relapse and remit', and it may vary from week to week, day to day, or even hour to hour.