

ME - A Guide for the Non-Sufferer

What is ME?

ME is an illness. ME stands for Myalgic Encephalomyelitis — which is a bit of a mouthful, but basically *means muscle (myalgic) and head* (encephalitic) symptoms. ME is also known as Post Viral Fatigue Syndrome (PVFS) or Chronic Fatigue Syndrome (CFS), because it often follows on from a viral infection. The disease is known by other names elsewhere in the world; in the US for instance it is called Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS).

How does ME start?

Often ME will start after an ordinary viral infection — flu, chickenpox, even a cold. 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 are the symptoms of ME?

As its name suggests, ME mainly affects the muscles and the head; muscle symptoms include severe fatigue on exercise, muscle pain and spasms. It is important to appreciate that the kind of fatigue experienced by many ME sufferers is quite different from the straightforward 'tiredness' most normal people have experienced. ME sufferers have likened the fatigue to 'having their plug pulled out' or being totally drained of energy. Unlike many other illnesses, exercise may make things worse. Any physical activity — even walking up or down stairs may put some ME sufferers in bed for days or weeks, 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 are likely to 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 the more exhausted the sufferer is 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 'ill all over' and experience many flu like symptoms; nausea, shivering, fever and aching joints. They may feel cold very readily and generally over react to heat and cold. Some unfortunate sufferers may be in constant unremitting pain.

Digestive problems are common' constipation or diarrhea, gas bloating and bowel pain.

Depression and emotional problems are often a part of ME but it is important to realise that these are a symptom of the illness and not its cause. Some sufferers are very emotionally volatile and unpredictable, they may get angry or depressed and for no apparent reason, or even cry at the slightest upset. This may be due to the illness affecting the nervous system.

What causes ME?

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

Is ME a 'new' disease?

ME has been around, under different names, for at least a century. It was probably seen before then but perhaps in a few people. So, it is not a 'new' disease but rather a newly recognised disease — and probably much more common.

Why is ME so controversial?

There are a number of reasons for this:

- There are such a variety of symptoms involved in ME that it is a difficult disease to define clearly and doctors don't like illnesses that won't fit into neat diagnostic pigeonholes.
- There are no clear tests to diagnose ME — it has to be diagnosed by doctors using 'clinical judgement' ie listening to the patient's description of their symptoms. Doctors often seem unwilling, or unable, to do this.

- There is very little satisfactory 'orthodox' medical treatment for ME.
- Some of the symptoms of ME overlap with illnesses that doctors' label as 'psychiatric' disorders so ME has tended to be lumped in with these conditions in the past.

How many people suffer from ME?

ME is not 'Yuppie Flu'. This unfortunate tag came from the United States and was probably invented by the US media. In fact ME strikes people of all ages (including very young children and very old people) from all social classes. There do seem to be more women than men with ME and the reasons for this are not known. One thing is true of the vast majority of people with ME — they want to get better. The idea that people with this illness somehow 'want to be ill' or that they are 'malingering' is absolute nonsense. Most them had an active enjoyable lifestyle before becoming ill and would like nothing more than to return to it.

How long does ME last?

Many people experience a period of what is known as 'post viral debility' after having flu for instance. This 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 six months, and the symptoms correspond, then it may be considered to be ME.

ME can last anything from a few months to decades in some unfortunate victims.

How ill are ME sufferers?

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 most of the time, occasionally accumulating enough energy to leave their wheelchairs for only a short while.

Those who are mildly affected may still be working full time, appear pretty normal, but may be having to rest every evening and weekend just to maintain their energy levels at work. 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 follow a course of 'relapse and remit' and it may vary from week to week, day to day or even hour to hour. So, don't be surprised if one week an ME sufferer is up and doing normal things and the next, they are in bed most of the time.

Is there any treatment for ME?

Although there is very little that orthodox medicine can do for ME sufferers, many have benefited from a self-help approach and there are things that can be done to speed recovery. Many sufferers have allergies to foods or substances in the environment. So, you may come across sufferers who are on restricted and apparently quite bizarre diets there are good reasons for this (e.g. they feel really ill if they break their diet!). Similarly, some people with ME find that things like exhaust fumes, perfume or ordinary household chemicals affect them badly, so they won't go near them.

How should I deal with a person with ME?

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 that 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.

Sometimes an ME sufferer may appear quite stupid because they don't seem 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. Remember that because of the effects of the illness on brain chemistry, some people with ME may be a little emotionally sensitive. Try to take this into account if a sufferer is irritable or tearful for no obvious reason.

If you ask a person with ME to do something or to be somewhere at a specific time, make sure they write it all down as sufferers may make commitments and then be struck with a bad bout of 'ME memory' and forget all about them! They won't feel offended if you remind them. Above all — BE PATIENT!