

## **M.E: A Guide**

This is a guide designed for people who know someone living with M.E. It is intended to offer brief information and does not constitute or replace medical advice.

### **M.E. Facts and Figures**

#### **What is M.E?**

M.E. is an illness. M.E. stands for Myalgic Encephalomyelitis / Encephalopathy – which is a bit of a mouthful, but basically means muscle ('myalgic') and head ('encephalitic') symptoms. M.E. is also known as Chronic Fatigue Syndrome (CFS) or Post-Viral Fatigue Syndrome (PVFS). The condition is known by other names elsewhere in the world; in the US for instance, it's called Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS).

It affects people in a variety of ways, with common symptoms including fatigue, cognitive problems, memory loss, aches and pains, dietary and digestive problems

#### **How does M.E. start?**

Often, M.E. will start after an ordinary viral infection – flu, chicken pox, glandular fever, even a cold. It is possible for an apparently healthy person to come down with a viral infection, and develop full-blown M.E. 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 M.E. in this way.

#### **What causes M.E?**

It is not known, but there is good evidence that certain infections can trigger M.E. such as a viral infection (glandular fever, viral meningitis, viral hepatitis) or ordinary flu-like infections. M.E. is generally thought to be caused by a combination of factors.

#### **Is M.E. a 'new condition'?**

M.E. has been around – under different names – for at least a century. It was probably seen before then, but perhaps in far fewer people. So it isn't a 'new' condition – but rather a newly recognised condition – and probably much more common. In 2002 the government gave formal recognition to the illness.

### **How many people suffer from M.E?**

There are no statistics on the number of people suffering from M.E, but it is estimated that 240,000 people suffer in this country at any given time, of which approximately 25,000 are children.

### **What kind of people suffer from M.E?**

M.E. strikes people of all ages (including very young children and very old people), all social classes and all ethnic origins. There does seem to be more women than men with M.E, and the reasons for this are not known. One thing that is true of the vast majority of people with M.E, is that 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 of them had an active, enjoyable lifestyle before becoming ill, and would like nothing more than to return to it.

### **How long does M.E. 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 M.E, 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 M.E.

M.E. can last anything from a few months to (in some unfortunate cases) decades. Statistics show that twenty percent of people suffering from M.E. make a fairly complete recovery within one year. Sixty percent make a partial recovery in three to four years and twenty percent seem not to recover, though they may regain a better quality of life than when they first became ill. Sadly some become severely affected and are bed or housebound.

### **Treatment and recovery**

As yet, there is no cure for M.E. It is a long term chronic illness which can last for many years. Many people go on to make a full recovery and many more make significant progress. An important fact in recovery is pacing and managing the condition. This can help with quality of life as well as with recovery. It is vital that the person does not do too much and rests when necessary. This can mean an extended break from work, university or school.

### **Why is M.E. so controversial?**

There are a number of reasons for this:

- There is such a variety of symptoms involved in M.E, making it a difficult condition to define clearly and some doctors find it a problematic condition to diagnose.
- There are no clear tests to diagnose M.E. – it has to be diagnosed by doctors using 'clinical judgment' – i.e. listening to the patient's description of their symptoms and by an elimination of all other possibilities. It is difficult and time

consuming to reach a diagnosis. Doctors sometimes appear unwilling – or unable – to do this.

- The main 'evidence-based' medical treatments are Cognitive Behavioural Therapy and Graded Exercise Therapy, however these are not effective for all people and often the patient themselves is the expert on the illness.

- Some of the symptoms of M.E. overlap with illnesses that doctors label as 'psychiatric' disorders, so M.E. has tended to be lumped in with these conditions in the past.

## **What is M.E. like?**

There are many symptoms of M.E. Not every person with M.E. will have all of them, and severity and intensity vary between people.

### **Fatigue symptoms**

One symptom common to all people suffering from M.E. is an overriding and debilitating fatigue. This does not just mean 'tired all the time'. The intensity of the fatigue varies, sometimes depending on the time of day and often depending on what the person has done. Many people describe it as like a plug being pulled or a battery running out. The fatigue felt is often overwhelming and is a type of exhaustion that is physically painful for the person living with M.E.

Unlike in many other illnesses, exercise may make things worse. Any physical activity – even walking up or down stairs – may put some people with M.E. in bed for days or weeks, and even cause a major relapse. Sometimes, you will see people with M.E. 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 people have learnt how to 'save up' energy to enable them to do things, knowing exactly how much they can do – and what price they are likely to have to pay afterwards.

Often this fatigue means that the person will have to stop what they are doing immediately in order to rest. It is important to remember that the thing they are doing could be as apparently un-energetic as talking to you. Try not to get upset or angry when someone says they are too exhausted to talk with you – they really are too tired.

### **Cognitive functioning**

Cognitive functioning, or thinking, attention and memory, are often affected in CFS/ME. One very frustrating symptom is 'brain fog'. This feels a bit like having a head full of cotton wool or fog. Often, someone with M.E. is unable to concentrate for any length of time (a combination of brain fog and fatigue). Sometimes just reading or watching TV is too much attention-wise. Thus they may seem uninterested or not paying attention in conversation. Try not to get

angry when this happens – it may be frustrating not to feel listened to, but imagine how frustrating it is not to be able to listen.

### **Memory loss**

Memory can be adversely affected. People with M.E. have difficulty transferring things from short term memory to long term memory. They 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 person is, and the mental exertion, as well as physical, may itself be exhausting for people with M.E.

Making and keeping lists is extremely helpful, although sometimes it can even be hard to remember to write lists! It is very important to remain patient with a forgetful person suffering from M.E, they are not doing it on purpose and it does not mean that what they have forgotten is not important to them.

### **Aches and pains**

There are many physical symptoms of M.E. As well as the overwhelming fatigue, there is usually pain in the muscles or joints. This pain can be extremely uncomfortable and very difficult to treat. The pain may not be relieved by normal methods like aspirin or paracetamol. Many people also have very bad headaches. Again, these can be very difficult to relieve. Finding a comfortable sitting or lying position can help. For example raising the legs using cushions.

### **Diet and digestive problems**

There can be digestion problems, so the person suffering from M.E. may lose or gain weight. The digestive problems are often similar to Irritable Bowel Syndrome. Some people find that they develop food intolerances. For example, most people find that they are intolerant to alcohol. These are not allergies as such but can be just as disruptive and distressing. Eating the food to which the person is intolerant can produce a severe deterioration in symptoms. It is very important to respect the dietary needs of the person and not put them down as being a 'fussy eater'.

Depression and emotional problems are often an effect of living with M.E, but it is important to realise that these are symptoms of the illness and not its cause. Remember to be patient with someone who is appearing angry, anxious or depressed. This may be due to the illness affecting the nervous system or frustration from living with a chronic illness.

These are not the only symptoms experienced with M.E: people will often feel 'ill all over' and experience many flu-like symptoms: nausea, shivering, fever and aching joints. They may feel the cold very readily and generally over-react to heat and cold. Some unfortunate sufferers may be in constant, unremitting pain.

### **How ill are people with M.E?**

Like any other illness, M.E. affects everyone differently and some are more affected than others. The most severely affected people 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 a short while. Those who are quite mildly affected may still be working full time – and appear pretty normal – but may be having to rest up every evening and weekend just to maintain their energy levels at work. Even quite severely affected people may look healthy when you see them, but they will pay a price later.

M.E. 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 a person with M.E. is ‘up’ and doing normal things, and the next they’re in bed most of the time.

## **Understanding a Person with M.E.**

### **The importance of belief**

Over the years, M.E. has been called many derogatory things. It has also been suggested that it is not a ‘real’ illness, that people suffering from it should just ‘pull their socks up’. Attitudes like this are not only unhelpful, they can be very cruel to the person suffering from M.E. For many years people with M.E. have not been listened to, a situation which is thankfully now changing. So first and foremost it is important to BELIEVE the person. M.E. is a very real and distressing condition. People with M.E. do not want to be ill; unable to do all the things they normally enjoy doing. They want to be well and active and it can be enormously distressing to be unable to live a normal life.

### **How should I support a person with M.E?**

The most important thing to remember is that people with M.E. 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 conversations, which require very little energy from a healthy person, may be very exhausting for someone with M.E.

If a person with M.E. 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 person 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, somebody with M.E. may not seem to be taking in what you are saying to them - this is a problem with concentration and memory. They 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 person a second time.

If you ask a person with M.E. to do something or to be somewhere at a specific time make sure that they write it all down, as they may make commitments and then be struck with a bad bout of 'M.E. memory' and forget all about them! They won't feel offended if you remind them. Above all, be patient, understanding and helpful to their needs.

### **Ask questions and listen**

The best person to tell you how they are feeling and which symptoms they are suffering from is the person living with M.E. It can be very hard to describe how it feels to have M.E. to those who do not have it. Many people find that the description of it feeling like bad flu without catarrh symptoms is a good starting point. The most important thing is to listen to and believe the person. And of course, be sympathetic.

**For further information, Action for M.E. has a range of publications and support services available. Please contact our membership team for a free information pack:**

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