

So what is M.E?

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M.E. (Myalgic Encephalomyelitis/ Encephalopathy) is a chronic, fluctuating illness. It is also known as Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue Syndrome (PVFS). The illness affects many parts of the body including the nervous and immune systems. The most common symptoms are severe fatigue or exhaustion, problems with memory and concentration and muscle/joint pain.

It is estimated that there are up to 250,000 people with M.E. in the UK. It can affect men, women and children of all ages and from all social and ethnic groups. It seems to be more common to develop the illness between your early twenties and mid-forties.

What are the symptoms?

M.E. is a complex illness that affects people in different ways. It's common for symptoms to change and fluctuate. Everyone experiences an individual mix of symptoms but a good starting description would be to imagine having a bad case of flu (to give the joint aches and extreme fatigue) combined with a bad case of jet lag (to give the spaced out feeling, poor balance and difficulty thinking and concentrating). Common symptoms include:

- Overwhelming, debilitating and persistent fatigue or tiredness. The fatigue may appear straight away or it may take a day or two to kick in and is not relieved by sleep or rest. This delayed reaction is a distinctive feature of M.E.
- Feeling generally unwell, similar to feeling like you have the flu all the time. A sore throat with or without swollen glands.
- Pain is common and can be felt as aching in the muscles and joints, pins and needles, muscle twitching and headaches or migraine. This pain can be extremely uncomfortable and very difficult to treat.
- Sleep difficulties such as needing to sleep excessively or not being able to sleep, un-refreshing sleep, waking in the early hours, light, dreamy, restless sleep and sleep reversal (for example, sleeping from 4am till midday).
- Cognitive functioning, or thinking, organising thoughts, attention and memory, are often affected in M.E. 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.
- 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 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.

- Problems with the digestive system such as nausea and loss of appetite, indigestion, excessive wind, bloating, stomach cramps and alternating diarrhoea and constipation.
- Problems with the nervous system including poor temperature control, sweating, dizziness and difficulties with balance and vertigo. 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.
- Increased sensitivity to alcohol, medication, some foods, bright lights, noise and odours.

Controlling symptoms

There isn't a magic bullet that can cure M.E. but there are a number of approaches that can help with symptoms. The most common symptoms that can take over and get in the way of recovery are sleep disorders, pain and mood problems like depression and anxiety. Your GP will be able to assess your situation and discuss medication, therapies and self-help strategies that might be beneficial.

Why is M.E. so controversial?

There are a number of reasons for this:

- Often, to the casual observer, the patient looks quite well but then its only when the patient is having a good day that they are out and about to be seen. When they are having a bad day and look and feel dreadful they will probably be in bed all day.
- There are 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 Pacing, 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.