*Chapter 5*

# M.E. - The Diagnosis

At the time of writing this book, there is no test for M.E. which gives a clear *yes* or *no* in 100 per cent of suspected cases.

It has been suggested that, as there is no treatment and you just have to live with it, there is no point in going to your doctor if you suspect you may have M.E.

A TV programme in the UK set out to show that getting a diagnosis of M.E. had not helped those patients who had been selected to take part in the discussion. The arguments were not convincing; however the programme probably sowed seeds of doubt in the minds of many M.E. sufferers, who were on the brink of having their illness accepted by their GPs and families.

The point of diagnosis was brought home to me very forcibly, when, on the same day that this particularly unhelpful TV documentary was shown, I read a report of a young man who had just committed suicide. He had been ill for over a year with a 'chronic virus: had typical encephalitic symptoms of M.E., and muscle fatigue. His work performance had deteriorated so much that his employers gave him notice to quit. The loss of a job to someone who is struggling and ill, and is not recognised as such by employers - who should otherwise have discussed sick leave, can be the last and fatal straw.

So there are good reasons for you to seek a diagnosis if you think you may have M.E.:

You need to rule out other conditions, some of which may be treatable - you may *not* have M.E.

You need a diagnosis, in order to apply for time off work or a change to part-time work, to apply for Social Security benefits, home help, retirement pension, etc.

If you are at school, you need the diagnosis to allow you to rest at home when ill, without your parents being prosecuted for your non-attendance (yes, this does happen to parents of children with M.E., hopefully less now that the illness is better recognised).

You need to know if you have a genuine illness in order to stay sane. To be told that your inability to stand up, to work normally, to think or live a normal life is not psychological is a wonderful relief, and may save some from suicide.

Through knowing what is wrong, you can start to reorganise your life, and come to terms with the illness.

Getting a diagnosis is, for many, the starting point of improvement. Battling on in ignorance of the problem is a sure way to get worse.

You need all the support and understanding you can get.

It is hard for your doctor, family and friends to supply this when they do not realise that you are really ill.

The more experience your doctor has of patients with M.E., the better his or her ability to help you and other sufferers.

Through getting a diagnosis, you can be put in touch with others through patient organisations.

If you have *not* got M.E., you will be very glad to know it. Other possible reasons for the symptoms and fatigue can be discovered and dealt with.

With so much publicity about the illness in the past year, a good number of people are going to their GPs to say 'Have I got M.E.?' when they may just be overtired or run down through inappropriate lifestyle. This puts doctors in a quandary, because M.E. is not a disease which is taught in medical schools, or seen much in general hospital wards; and if it is, it is called something else, such as heart attack, abdominal pain, or nervous collapse of unknown cause.

The diagnosis is made on the basis of a patient's history, and lack of objective signs of other disease. There are sometimes abnormal signs on physical examination of the nervous system, and there are a number of laboratory tests which may help confirm the diagnosis (but even if the results of these prove normal, this does not rule out M.E.)

A list of symptoms typical of M.E. is given in Chapter 1. The cardinal symptom is *fatigue,* unrelieved by rest, and made worse by exercise.

When you go to your doctor, or to a specialist, do prepare some sort of history of your illness in writing, in advance. Write down:

- When you last felt well
- All infectious illnesses you have had, especially any that occurred around the time of the onset of your current symptoms
- Anything else that happened to you just before the onset
- If anyone in your family or work circle was ill at the same time, and if any of them developed symptoms of M.E.
- Your main symptoms at present
- Whether the symptoms have been constant or intermittent
- How your illness has affected your lifestyle - work, family life, income, social activities
- How much exercise you could take when you were well, and what you can do now without ill effects
- Anything that seems to make you better

This preparation will help the doctor, and save you from forgetting important information at the time of consultation - most M.E. patients have a bad memory which only gets worse when under a cross-examination!

If possible, take along a relative or close friend who knows you very well, and who can add his or her observations about any changes in you since the illness, should your mind become a blank.

If your illness has begun shortly after a viral infection (sometimes up to 6 weeks later), and you have classical symptoms, then the diagnosis is fairly easy. It is much more difficult in the case of someone who has become unwell gradually, with no obvious precipitating infection. For these people, it is especially helpful to try and remember past infections or bouts of unwellness, which may be as seemingly trivial as a 24-hour tummy bug while abroad.

Your doctor should enquire about childhood illnesses, previous health, operations, and drugs taken (especially antibiotics). Also about the health of your parents and siblings, and a family history of allergies, undue infections, or M.E.-type illness.

A full physical examination should be carried out, including blood-pressure, examination of heart, lungs and abdomen, a search for enlarged glands, and tests of neurological function and muscle power.

There is rarely extreme muscle wasting, but there may be some loss of muscle bulk, especially in the thighs. This is usually symmetrical, unless one limb is worse affected.

Neurological tests may show brisk tendon reflexes, but the *plantar* response is usually normal (the big toe curls down when the sole of the foot is lightly scratched), and there is no *clonus* (jerky contraction of a muscle when suddenly stretched). Two tests which are sometimes abnormal are the vibration sense and the Romberg' test (sense of balance with eyes closed).

Simple tests of muscle power may be normal.

However, if muscles are exercised - such as the patient squeezing a rubber ball for one minute, or being sent to climb 40 stairs (if able), the muscles used will be found to be weak, the weakness lasting several hours or several days.

There is almost invariably muscle tenderness. Careful fingertip feeling of the thigh or upper back (trapezius) muscles usually reveals points of great tenderness.

A key factor in arriving at a diagnosis of M.E. is the exclusion of other diseases which might be causing fatigue. Briefly, these would include chronic infections, endocrine diseases, nervous system disorders, cancer, muscle diseases, auto-immune disorders, and primary psychiatric illnesses.

There are a number of blood tests which should be carried out, as well as urine testing, and then possibly more specialised investigations for M.E. or to exclude other conditions. Muscle biopsies, electromyograms, and the enterovirus test (VP1) are not routine tests, but may be used as part of some research programme.

Nevertheless, ultimately the diagnosis rests on a careful history, and exclusion of other conditions. Once a doctor has seen a patient with M.E., the symptom picture is not forgotten. It is fair to say that many doctors are unsure about recognising the illness, or even believing in it, until they know one of their patients, one of their family or a colleague who develops it; this experience usually dispels any scepticism, and any other patients in the practice who have M.E. will benefit thereafter.