

SO, YOU HAVE BEEN DIAGNOSED AS SUFFERING FROM M.E.!

Advice to New Patients

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For some people this diagnosis may come as a shock and for others a relief. Most will be puzzled unless a complete explanation has been given, for there is little to be found under this heading in standard medical books.

WHO MADE THE DIAGNOSIS?

A recent postal survey disclosed that 38% of ME patients learnt their diagnosis from a Hospital Consultant, 27% via their GP and the remaining 10% from various sources including private or alternative medicine. It has been my experience, that the self-diagnosed patients are often as accurate as the doctor, provided they check their facts carefully with a reliable source of information.

Nevertheless, for reasons explained below the diagnosis of ME at present depends upon clinical judgment rather than laboratory test. It is therefore essential not to make two mistakes. First ME is a common illness and often co-exists with other common disabilities such as anaemia, high blood pressure, rheumatism, gall bladder disease and appendicitis. It is important not to miss the second diagnosis, Second and for the same reasons, new symptoms occurring after the diagnosis of ME should be investigated and not automatically assumed to be part of the same illness.

WHAT DO OTHER PEOPLE THINK?

On spreading the news of your diagnosis to friends, relatives or medical attendants you may be surprised and hurt by their reactions. Some of them are quite likely to say they do not believe in ME, that you are hysterical and would be well advised to pull yourself together and go out jogging!! I feel deeply for you if this is the case. It is bad enough to be ill without enduring ridicule as well. Unfortunately this happens in other illnesses and tells us more about the people who make the remarks than it does about the patient. You may comfort yourself by remembering that anyone who mentions "hysteria" is undoubtedly a poor scholar. The term actually means "a wandering womb" and automatically excludes children, male patients and ladies who have had a hysterectomy. It seems more likely that people are trying to suggest that you have a "hysterical personality" or are dramatizing your symptoms. I have met very few patients that come into this category unless they also suffer from a separate psychiatric illness known as manic depression, in which there are episodes of mania as well as of depression. Here lies another problem for the word "depression" is commonly used both to describe unhappiness and anxiety (noted in many prolonged illnesses) and to denote a hereditary defect of brain chemistry in which physiological stress control is disturbed. Everyone is subject to the first type of depression and up to 20% of the population to the second. Therefore one or both may coincide with ME but must not be confused with it. The treatment of psychiatric depression or mania requires drugs and the skill of a doctor who understands psychiatry as well as ME, if there are not to be harmful side effects.

Unhappiness needs only the love and support of relatives and friends. In my experience the average patient with ME is hardworking, disinclined to rest and frequently conceals the illness in order not to let down colleagues and relatives, hardly the picture of a hysterical exhibitionist of mental derangement.

WHAT IS ME?

The term “Myalgic Encephalomyelitis” (ME) means painful muscles and inflammation of the brain and spinal cord. It doesn't exactly describe the many and varied symptoms of the illness. Neither does “poliomyelitis” (Polio) explain that the commonest manifestations of that illness are headaches, sore throat or “summer flu” rather than inflammation of the white matter of the spinal cord, but the two disabilities have much in common. Both have become modern diseases of cleanliness, that is to say, virus infections associated with warm weather and primitive sanitation which for centuries past have afflicted children. The occasional child might have had nasty symptoms, become paralysed or died, but the vast majority were symptom free and carried their immunity into adult life. (Today we copy this natural control pattern by spreading a mild form of polio virus on sugar lumps, knowing that it will circulate and immunise the entire community). Unfortunately there remains approximately seventy other similar (non polio) enteroviruses for which no form of vaccination is yet available. Hygiene, cool summers and affluence have limited their circulation in this country. Many children escape infection only to become more severely ill when they are older, as so often happens with rubella, chicken pox or mumps when acquired in adult life. Enteroviruses, which are associated with ME live in the bowel and are usually spread by symptom free toddlers to parents, nurses and doctors by direct contact (e.g. the handling of diapers, potties and bed pans). Indirect contact with sewage, contaminated pools or beaches, unhygienic food, flies etc. involve the whole population, especially travellers to hot countries with primitive sanitation. School children and teachers are at risk from respiratory spread.

WHAT CAUSES THE SYMPTOMS OF ME?

Enteroviruses infect the body via the mouth and are dealt with initially by the tonsils and glands lining the bowel. In most cases there are no symptoms and another eventually replaces the virus. In non-immune children and adults there may be a “primary illness” which is either respiratory (sore throat, bronchitis “flu or glandular fever” like) or gastro intestinal, it can also involve various glands, the heart, the brain (meningitis encephalitis) or cause acute dizziness and other nervous manifestations. A very small number of people may then suffer the complication of ME – rather like the paralysis that affects a minority of people with polio. It would appear that the virus escapes from its natural resting place in the bowel and travels via the blood to the brain and muscles. The reason for this is not exactly known, but (as in polio) complications appear to afflict those who have been stressed during this period especially in terms of physical exertion, though their immune system is normal. The commonest symptoms of ME are pain and weakness of the muscles following minimal exercise (sometimes after an interval of 24-48 hours). This is caused by chronic and persistent virus infections of individual muscle fibres. To understand the process it is necessary to study normal athletic training where the aim is to keep the muscles working on their initial (aerobic) energy cycle for as long as possible. Oxygen is used and harmless waste products such as carbon dioxide and water are easily disposed of. Further exercises then involve an anaerobic cycle producing lactic acid. If muscular stress continues with a build up of acid (as in marathon running) prolonged aching, fatigue and cramps will result. Rest, to obviate this accumulation is an essential part of the training.

Patients with ME owing to virus interference with cell metabolism are “marathon runners” almost from the start and above all, require rest. They must stop before they get tired and if this is not possible take adequate rest afterwards, if the symptoms are not to be long lasting.

Research has shown a similar interference with the energy cycle in the brain, an organ which is exceptionally sensitive to lack of oxygen and energy in the form of glucose. In ME the brain's computer functions are disturbed, regulation of temperature control, breathing, heart rate, blood pressure, blood sugars, sleep rhythm and many other automatic functions is impaired, filing of memories and the ability to concentrate and recall words are often lacking. Other nervous disturbances include pain, tingling and problems with vision and hearing. Research has also shown that the causative virus persists in the bowel for years rather than weeks, causing intermittent "irritable bowel" symptoms. There may be many other disabilities in different patients and symptoms vary from day to day. Relapses and remissions occur, depending upon whether the viruses are circulating in the blood stream or "hidden away" in cells. It is important to report all symptoms when giving your history. There may be connections between them that you have not realized and it is quite easy to feel one is going mad when so many diverse things happen at once. It is most unlikely that by the time you develop ME you will be infectious to friends and relatives. It is much more probable that one of them infected you way back during the "primary illness" and then developed their own immunity. It is no more possible to catch the complication (ME) of an entero-viral infection than it is to catch paralysis from a paralysed polio patient.

CAN THE DIAGNOSIS OF ME BE MADE BY A LABORATORY TEST?

At the time of the primary respiratory, gastro intestinal or other illness, if samples from the throat or bowel are taken very quickly, the virus may be isolated but within a few days a powerful immune response occurs and all viruses become coated with a protective protein coat (antibody) and can no longer be detected.

ME is not usually diagnosed for at least six months as all enterovirus infections have a tendency to relapse two or more times before recovery. It is only when the relapse continues and the patient remains ill that we recognize the complication of persistent virus infection called ME. By this time virus isolation is not possible and research procedures remain the only possibility. It is also too late to pick up short acting antibodies (Coxsackie B virus Igm) except possibly in a relapse, because they disappear when the virus is no longer multiplying and has reached a resting stage. Long acting antibodies (Coxsackie B virus Igm as demonstrated by a cumbersome and expensive neutralization test) may remain for a lifetime. Antibody tests are difficult to interpret because healthy symptom free carriers may also be positive. In epidemic years and for a long time after, it is impossible to distinguish between the sick and the healthy by serological tests alone. At present, we only have the Coxsackie test available in the NHS and research procedures which are expensive or invasive (Vpl muscle biopsy) are reserved for the few. For this reason a "positive" or a "negative" laboratory test can only be interpreted in conjunction with the clinical symptoms. Newer laboratory methods are in the pipeline, but until that time there is no substitute for a good clinical examination. Other laboratory test (routine hematology and biochemistry) are valuable for two reasons. First, they may indicate a virus infection or complications in various organs: second, they may provides evidence of unassociated but treatable diseases (e.g. anaemia, diabetes, kidney trouble).

TREATMENT

Although drugs have been developed which are active in preventing respiratory infections due to enteroviruses and which stops the virus from causing complications in similar animal diseases, they are not yet on the market. In fact they are unlikely to attract research fund unless the serious problems of human infection are made generally known. In general anti-viral drugs are of limited use in treating acute virus infections but useless to control spread or prevent recurrence. All the major advances in this field have been achieved by immunization (polio, small pox etc.) and public health measures such as clean water and good nutrition. Gamma Globulin (borrowing antibodies from other people) has been shown

to be protective before the infection is contracted (e.g. to prevent Hepatitis A during travel abroad) and has had limited success in modifying virus infections when the causative agent is still circulating in the blood. Experiments have shown that it cannot clear persistent infections inside cells. Hence the variable reports from patients with ME who have been treated this way.

Symptomatic treatment is the most important aspect and this must include adequate rest, as described above, to prevent fatigue arising from crossing the anaerobic threshold of muscular action. Only the patient or the parent can decide when this fatigue sets in, as energy levels vary from day to day. Each individual must adopt the motto stop before getting tired or, if this proves unavoidable, take adequate rest afterwards. Train as strictly as an athlete would before a big race. It requires considerable self-discipline and may involve lessons in relaxation. With luck and determination periods of well being will return and increase in duration. Remember also to relax and enjoy them. Never try to do the Christmas shopping or catch up with DIY jobs during such a respite, or you may be disappointed by a relapse. Experience has shown that the brain symptoms are likely to clear first if muscular stress is avoided. Students and school children can often undertake study once again.

WHAT TO DO

Plan your life according to priorities; you will not be able to do everything at first. Try to arrange flexi time with employees or teachers. If at home, rest midday, or after shopping and taking the children to school. Plan to "crash out" if you come back from full time work and don't go out again in the evenings except at weekends. Children with ME often do better with part time home tuition. Fill your home and garden with energy saving devices and always consider simple remedies such as warmth for pain and light reactive sunglasses for eye strain. Walking sticks or pram pushing and bicycling on the flat may make locomotion easier.

WHAT NOT TO DO

Never take tablets for pain, allergy, depression etc without careful discussion, as some drugs are detrimental to your problems. ME is not caused by candida infection, over breathing, taking antibiotics, vitamin or mineral deficiency, dental amalgam nor sugar, It is a virus which lowers your energy level and you need a good all round diet, divided into small regular snacks. Patients who are inclined to feel washed out or faint if they miss a meal should carry glucose tablets as their blood sugar may be poor. Try to avoid sudden climatic changes, alcohol and smoking all of which may be deleterious to patients with ME. Vaccination, general anaesthesia, surgery, steroid or anti rheumatic and psychotropic drugs may be associated with a relapse but are obviously necessary under appropriate circumstances.

Pregnancy often induces a feeling of well being but a prolonged labour can be associated with exhaustion. Long term planning will be required to overcome the problems of broken sleep and tiredness and the care of young children.

Sexual difficulties arising from fatigue may occur in both sexes. If you are feeling unhappy or suicidal remember you are not alone. Call a friend without delay or ring or ring ME North East for local support and group telephone numbers.

WHAT OF THE FUTURE?

No doctor no matter how experienced can predict the eventual outcome of ME in the present state of knowledge. In general, young people who are able to rest and pace themselves from the start do well and I have known several who have made a complete recovery within three years. The disease tends to fluctuate for 3-5 years in most patients until they settle down to a steady energy level. In some cases, this is very low and in others, almost normal. A few patients go downhill from the start, while others ostensibly make a complete recovery. The liability to an occasional relapse appears life long. No patients with ME need ever despair or feel alone. There are thousands of sufferers in this and other countries who have banded together in support groups such as ME North East. Their aim is to provide information, their expertise is at your disposal, but in return we need your support and advice in order to help others. You only have to pick up the telephone.

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