

ME BRIEF

ME/CFS

MYALGIC ENCEPHALOMYELITIS - CHRONIC FATIGUE SYNDROME

DIAGNOSIS

ME/CFS has a distinctive cluster of characteristic symptoms that reflect specific areas of pathogenesis. This gives it a unique clinical picture that is easily recognized by doctors familiar with it.

Clinical evaluation begins with a thorough history, an extensive clinical examination and laboratory testing. Although standard tests are useful to exclude other possible organic illnesses, they may be inadequate to reveal the distinct abnormalities found in ME/CFS patients. Immune and gastrointestinal dysfunction and inflammatory markers are hallmarks of ME/CFS and it is recommended that specific tests be used. Information about the recommended tests can be found in: ME/CFS: A Clinical Case Definition and Guidelines for Medical Practitioners, *Carruthers, van de Sande, 2003* - the so-called Canadian Criteria.

The current recommendation is that a diagnosis first be given after symptoms have been present for at least six months. However, delay greatly increases the chance of long-term convalescence and permanent damage/disability. It is therefore of the utmost importance that the disorder be diagnosed swiftly.

SYMPTOMS

The primary symptoms of ME/CFS are: post-exertional malaise, mild fever (37.5°-38.6°), sore throat, swollen lymph nodes, muscle weakness, muscle/joint pain, headache, memory and concentration problems, sleep dysfunction and fatigue. Symptoms can have an acute or gradual onset. Mental as well as physical fatigue are characteristic in that they are unrelieved by adequate rest. These primary symptoms must substantially reduce the patient's pre-onset activity level.

Besides these primary symptoms - which are present in almost all patients - there are also a number of secondary symptoms which strongly affect quality of life. These include: immune dysfunction, digestive system complaints, food allergies and intolerances, blood pressure irregularities, weight changes, cold extremities, balance problems, and eye problems.

It is difficult to accurately forecast a long-term prognosis for this illness. However, the sooner the patient is diagnosed and appropriate treatment is begun, the greater the chances the patient will at least partially recover and retain a reasonable life quality. It is of the utmost importance that the patient quickly learns to pace activities and establish a balance between sufficient rest and adequate movement, as excessive activity leads to set-backs and even permanent disability. Because of the great degree of variability from patient to patient, this activity/rest balance will be highly individualized. It is imperative that sufficient rest be allowed early on in the illness as this gives the best prognosis for recovery. Complete recovery rates are very low - between 2 - 8%. This is partly due to delayed diagnosis and lack of proper treatment early on in the illness because doctors fail to recognize the disease. **ESME is focusing on educating healthcare personnel because education will lead to earlier diagnosis, proper treatment and, consequently, a greatly improved prognosis.**

PROGNOSIS

Like other illnesses, ME/CFS does not affect everyone in the same manner or to the same extent. Some patients suffer from all of the symptoms to a severe degree and are entirely bedridden. Others have only a few symptoms to a minor degree and may be capable of an almost normal life. The majority of the patients fall between these two extremes. The simplest activities - intellectual as well as physical - can cause an increase in symptoms or even provoke a decline that lasts weeks or months. The illness has a very serious impact on the patients' lives, as simple things like taking a shower, walking up stairs or even lifting a glass may not be possible on some days.

It is typical of the illness that there is a large fluctuation in the number and severity of symptoms during the course of the day or week. Even on good days, the patient may feel ill for the larger part of the day. However, there can be low-symptom "windows" when they feel less ill and can appear to function normally. This extreme swing in symptoms has a number of consequences for the patient and those around them. A patient's family, colleagues and social contacts may have a hard time understanding the seriousness of this disease because the patient can at times appear to be "healthy." This causes difficulties in the patient's social, professional and private life - as well as problems with the medical community that lacks knowledge of the illness.

COURSE