

## APPENDIX C

### Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in Children and Adolescents—Fact Sheet

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex disease characterized by the body's inability to produce sufficient energy for the normal range of human activity. There is severe, overwhelming fatigue with a substantial loss of physical and mental stamina. The patient's energy reserves are substantially reduced. The cardinal feature is a worsening of symptoms and malaise (feeling ill) following minimal physical or mental exertion. This can persist for hours, days, or weeks and is not relieved by rest or sleep. Other symptoms include: cognitive problems ("brain fog"), unrefreshing or disturbed sleep, light-headedness, a variety of painful conditions, and other symptoms in multiple body systems.

ME/CFS occurs worldwide. In different countries, it is labeled chronic fatigue syndrome, myalgic encephalomyelitis or the acronym, ME/CFS. A new name, systemic exertion intolerance disease (SEID) has been proposed, but is not in general use. The name "chronic fatigue syndrome" has been criticized because it can be confused with "chronic fatigue," which is common in many other illnesses.

Myalgic encephalomyelitis/chronic fatigue syndrome usually occurs as sporadic (isolated) cases, but in 20% of patients it affects more than one family member. Clusters of cases or outbreaks of the illness (epidemics) have been found worldwide and in several of these outbreaks the illness has been prominent in schoolchildren.

#### ME/CFS in Children and Adolescents

At least one million Americans are thought to have ME/CFS and a substantial but unknown number are under the age of 18 years. Adolescents 12–17 years old are more likely than younger children to develop ME/CFS, but children as young as four years of age have developed the disease. In adolescents more girls than boys have ME/CFS.

#### Cause of the Disease

The cause of ME/CFS is unknown, but several factors may be involved. In some families, genetic factors may produce a susceptibility to the illness. Frequently the illness follows an acute infection such as infectious mononucleosis and immune system changes found in ME/CFS are similar to changes found in some viral infections. No known infectious agent has been shown to be the cause and in sporadic (non-epidemic) cases, the illness is not thought to be transmissible by casual contact. Occasionally, ME/CFS is triggered by a toxin, an immunization, or by major trauma. ME/CFS is not a psychological illness. Depression and anxiety can occur secondary to ME/CFS, as occurs in other chronic illnesses, but Major Depression and ME/CFS can be distinguished by behavioral, immunological, and hormonal testing.

#### Symptoms and Diagnosis

The diagnosis of ME/CFS is made from the characteristic pattern of symptoms and the exclusion of other fatiguing illnesses

because there is no medical test for the disease. Many patients remain undiagnosed. The main diagnostic features of the illness have been incorporated into several different case definitions. We recommend the following clinical diagnostic criteria which have been found to be useful in pediatric patients:

- There is loss of mental and/or physical stamina and a substantial reduction in ability to take part in personal, educational and/or social activities.
- There is a new onset of fatigue that is not the result of ongoing exertion and is not relieved by rest. Fatigue can worsen with prolonged upright posture.
- Normal activity or mild/moderate exertion is followed by malaise (feeling ill) and worsening of ME/CFS symptoms. Recovery can take days, weeks, or months
- Sleep is unrefreshing, with disturbed quantity or rhythm that can include daytime hypersomnia, nighttime insomnia, day/night reversal.
- Any of the following cognitive problems can be present: difficulty in concentration, impaired short-term memory, difficulty understanding information and/or expressing thoughts, difficulty finding words or numbers, absent mindedness, or slowness of thought. Cognitive problems can worsen with prolonged upright posture and/or with physical or mental activity.
- Pain can be widespread or localized. Commonly seen are: chronic daily headaches, pains in the muscles, the abdomen, the joints, and/or the lymph nodes and/or sore throats. Pains can be worsened by prolonged upright posture. Rarely is pain absent.

Myalgic encephalomyelitis/chronic fatigue syndrome symptoms often fluctuate significantly in intensity during the day, or from day-to-day. To diagnose ME/CFS some or all symptoms must be present every day. The symptoms' intensity must be mostly moderate to severe and symptoms must have persisted or recurred for at least 6 months (a provisional diagnosis and appropriate management can be instituted before 6 months). Other fatiguing illnesses must be excluded by history, physical examination, and medical testing.

Other symptoms that can be present in many, but not all, pediatric patients are:

- Orthostatic intolerance: prolonged upright posture can induce lightheadedness, increased fatigue, cognitive worsening, headaches and/or nausea.
- Hypersensitivity to light, noise, touch, odors and/or medications.
- Thermo-regulatory imbalance: low body temperature, intolerance to heat and/or cold, or cold hands and feet.
- Gastrointestinal symptoms: abdominal pain, nausea, or anorexia.

Young people with ME/CFS often do not look ill but can appear noticeably pale. Routine blood tests are frequently normal, but specialized testing can show abnormalities in patients' immune, nervous or cardiovascular systems, or in cellular energy production.

Myalgic encephalomyelitis/chronic fatigue syndrome has often been misdiagnosed as School Refusal (school phobia), or as

Munchausen's syndrome by proxy (a condition in which a parent fabricates their child's illness).

### Progress and Recovery

Myalgic encephalomyelitis/chronic fatigue syndrome in adolescents usually starts suddenly with a fever and flu-like symptoms. Sometimes the onset is gradual. In younger children, a gradual onset over months or years is more likely. It can be difficult to diagnose ME/CFS in younger children because they may not recognize that their fatigue and other symptoms are abnormal. The diagnosis can be made retrospectively when the child is older. The first sign of the illness might be the child's marked limitation of activity, noticed by a parent or teacher. Young people with ME/CFS can be very ill at the onset of the illness, but because routine blood tests are frequently normal, the diagnosis is often uncertain. Even when no other illness is found, a definitive diagnosis of ME/CFS cannot be made for 6 months, but a provisional diagnosis can be made sooner. Early diagnosis can lessen the impact of the illness by ensuring an appropriate management plan.

The severity of ME/CFS varies. Some young patients are severely disabled and bedridden, while others can go to school and a few can even do sports. Most are between these extremes. Over time, slow improvement is likely. Recovery rates are uncertain but rates of up to 40% have been reported. Dramatic improvement is more likely to occur in the first four years. Remissions and relapses are common. Relapses can be caused by overexertion or

by infectious illnesses. Young patients whose health improves to near pre-illness levels are likely to find that they need more rest than their contemporaries.

### Management/Treatment

Establishing the diagnosis of ME/CFS can relieve uncertainty in the minds of the patient and the parents. There is currently no medication or intervention that will cure the disease. Management differs between individuals. Determining the optimum balance of rest and activity (pacing of activities) can help prevent post-exertional worsening of symptoms. Medications are helpful to treat pain, insomnia, and orthostatic intolerance. Young patients with ME/CFS commonly respond to lower dosages of many medications. Advice on nutrition can be helpful. Supportive psychotherapy can sometimes benefit mildly affected young patients, but inflexible, graded exercise (GET) is harmful and can lead to worsening of symptoms.

### Education

Myalgic encephalomyelitis/chronic fatigue syndrome is the most common medical cause of long-term absence from school. Most students with ME/CFS fall behind in their education. Students with ME/CFS might need a personalized school schedule and the school might need to provide reasonable accommodations and/or home tutoring. Legal and procedural requirements for students to receive services for their disabilities vary significantly from place to place.