

CHRONIC FATIGUE IMMUNODEFICIENCY SYNDROME/MYALGIC ENCEPHALOMYELITIS

Chronic fatigue immunodeficiency syndrome (CFIDS), also referred to as myalgic encephalomyelitis (ME), affects people of all ethnicities and income groups. Like many autoimmune and chronic pain conditions, it is more common in women (as many as 70 percent of patients) than in men. The causes of CFIDS are unknown. One theory is that it starts with an infection or is a neurological reaction to infection; the condition may result from a defect in an enzyme (Rnase-L) that the body uses to inactivate viruses. Symptoms can include incapacitating exhaustion, generalized weakness, cognitive problems, increased viral symptoms, nonrestorative sleep, exercise intolerance (when exercise makes symptoms worse), chemical sensitivities, and chronic physical pain. Some of us who have CFIDS are able to function at a reduced level, while others of us are completely disabled.

After four years of struggling up these three flights of stairs to my classroom, I can't do this anymore. Everything hurts. I am out of breath. It's only 8:00 in the morning. I will try to cover up my mind-numbing exhaustion, but when? My brain shuts down, my speech slurs and I feel like I am trapped in a bad charade. As I give all of myself to someone else's children, I am incompetent. Then, I go home with nothing left for my own kids.

Researchers and clinicians are not sure whether CFIDS is the same illness as ME or, possibly, fibromyalgia. The World Health Organization (WHO) defines ME as a neurological illness and uses two alternate names for it, chronic fatigue syndrome (CFS) and post-viral fatigue syndrome (PVFS). Subsets of patients display

differences in the onset, symptoms, and severity of illness. Many patients may not get an accurate diagnosis, because CFIDS/ME is one of several conditions with similar body pain and weakness (post-polio syndrome, which occurs in survivors of both paralytic and nonparalytic poliomyelitis; chronic Lyme disease; fibromyalgia; multiple sclerosis; and lupus). It may also overlap with migraine, temporomandibular joint disorder (TMJ), irritable bowel syndrome, and multiple chemical sensitivities. Also, many practitioners are skeptical about CFIDS/ME and dismiss women with a referral to a psychologist.

My doctor said, "All working women with kids are tired. I can't find anything wrong. Things okay at home?" I look pale as candle wax with about as much energy as a doorknob. . . . That [appointment] started doctor shopping that yielded no results. To be a cooperative patient, I tried several long trials of antidepressants only to end up feeling progressively worse each time.

Symptoms

You may feel overall weakness and exhaustion and experience arm and leg muscle tremors. This lack of stamina and energy interferes with the ability to participate in normal daily activities. Rest does not relieve symptoms. Simple activity can lead to pain or the whole body aching, starting twenty-four to thirty-six hours after exertion. Aerobic activity can cause total relapse.

I was a successful rising scholar when I collapsed ten years ago. I was active, loved to ski, [and was] involved in the lives of my two children. It has been as if I had to watch my own death. If I had not had children, I would have committed suicide long ago, particularly during the periods of intense pain when all I could do was lie in bed. For years I did not have a single day I felt well. Imag-

ine the worst flu you ever had, and it never goes away—you think it can't get worse, but it does.

Exertion or standing for periods of time may bring on dizziness, light-headedness, and nausea with an irregular heartbeat (orthostatic intolerance). You may become sensitive to light, sudden noise, and odors. Some people feel jittery or anxious. Conversation might be difficult because of slurred speech and problems with recall, word retrieval, and understanding. It may become difficult to sort, sequence, and organize ideas and objects. Confusion and time disorientation can make it hard to finish tasks.

There is a test where patients are asked to put one foot in front of the other, hold their arms out, and close their eyes. A patient with CFS cannot hold that position for any length of time (I would im-

mediately fall over). A very few get dizzy; most of us just do not know where we are in space.

Changes in appetite, weight, and reaction to food can occur, including intestinal and bladder disturbances, irritable bowel syndrome, and new food sensitivities. You may have low blood sugar (hypoglycemia). Headaches, overall body pain, irritability, and mood swings are common. CFIDS/ME patients are often unable to get good-quality sleep, which makes symptoms feel worse. Some people have bouts of viral symptoms such as sore throat, tender lymph nodes, and sinus congestion. Some report hypersensitivity to medications and chemicals, and antibiotics are usually not effective. (To learn more, see "CDC Criteria for Diagnosing CFIDS" [W71] on the companion website, www.ourbodiesourselves.org.)

Nonroutine brain scans and blood tests of people with these symptoms sometimes show abnormalities, but these tests are not always available. Most advocacy organizations can provide information about tests and research, as well as hope and support for those of us struggling to cope with a complex and poorly understood condition.

Treatment

There is no cure for CFIDS/ME, but there is a range of therapies that may be helpful for symptoms such as headaches, pain, and sleep and balance disorders.

Since those with CFIDS respond differently to different strategies, you may have to try many treatments. Do your own research, network with others, listen to your body, and use trial and error. Feeling desperate after years of illness can make us vulnerable to "magic bullet" cures. When considering a new treatment, use caution, double-check information, and consider safety, benefit, and expense.

Rest, Exercise, and Nutrition

Moderating your activity level is crucial. Regular periods of uninterrupted rest are essential, but not complete bed rest, which can cause muscle atrophy and increasing muscle weakness. When you do feel better, don't rush back to normal activity, because pushing the body too hard or too quickly can result in a serious relapse. Mild stretching exercises and walking to keep your body in motion will help you maintain your physical conditioning. Don't push when your body tells you not to!

Diet

Dietary changes may help with stomach and intestinal symptoms. Certain foods may make you feel worse, particularly alcohol, caffeine, sugar,

wheat, and food additives. A high-protein diet and magnesium supplements may be beneficial. You might want to investigate vitamins B₆ and B₁₂, folates, SAM-e, glucosamine, and essential fatty acid supplements, especially the omega-3 fish oils. Other supplements that support mitochondrial (energy) function are beneficial for some people.

Drugs

Antidepressants are commonly prescribed to treat the underlying chemistry of many types of pain and fatigue. Low-dose antidepressant medications such as Elavil and Sinequan often improve sleep quality. Other drugs can be tried to manage pain and cognitive symptoms. Because many of us with CFIDS are very sensitive to drugs, it is best to start out with the lowest possible dose and increase if necessary. Experimental drugs—such as Ampligen—show promise, but they are available only in clinical trials and have not yet been approved by the FDA.

The pain and confusion are gone, and I can walk a mile (with the aid of a brace on one leg). After six months on the medication, which I must take via IV twice a week . . . I was driving a car and beginning an exercise program. Within two years I was hiking a bit again! I could walk on the beach! It was wonderful. But expensive.

About one third of people with CFIDS recover almost fully, but no one knows why. Some get a little better; others recover minimally if at all; still others have progressively worse symptoms over time. For many of us, the illness waxes and wanes, with periods of relative health interspersed with relapses. If you are very ill, a good support person in your life who can help you keep track of what seems to work and what doesn't is extremely important. Support groups and websites can help you sort through symptoms, treatments, and coping methods, includ-

