

Institute of Medicine committee releases report on ME/CFS

On February 10, 2015, the Institute of Medicine (IOM) Committee on Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome released a report titled [“Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.”](#) The IOM Committee’s work was supported by the Department of Health and Human Services (HHS) Office on Women’s Health and other HHS agencies.

The website of the HHS [Chronic Fatigue Syndrome Advisory Committee](#) includes the following comment about the IOM committee report: “With their recommendation of a streamlined, yet evidence-based set of diagnostic criteria, the IOM committee has taken a critical step toward assisting medical providers in making a diagnosis for those with this serious and debilitating illness.” The website also states that the HHS agencies are committed to working with partners, stakeholders, experts in the field, and CFSAC to review the report’s recommendations and appropriate next steps.

In 2011, CDC posted the CFS Toolkit on its website to provide an easy-to-use resource for clinical care. During recent months CDC scientists had been working with CFSAC and others to revise the CFS Toolkit. After publication of the IOM committee report, CDC decided to archive the CFS Toolkit. Those interested in reviewing the CFS Toolkit in its entirety can view the document below.

MANAGEMENT

In addition to an extensive medical history and physical exam, the best management plan provides individualized supportive and symptomatic treatment. Physicians should encourage patients to be proactive about managing their symptoms.

Symptomatic Treatment

The first step in managing CFS is to have patients prioritize symptoms from most severe to least severe. Next, physicians should identify underlying conditions causing the most problematic symptoms. These may include sleep disturbance, pain, weakness, light-headedness, memory or concentration problems, depression or anxiety.

Once the symptoms are identified, appropriate medications can be prescribed to relieve symptoms. CFS patients are frequently sensitive to medications, especially central nervous system (CNS) acting medications (sedating or stimulating). Therefore, consideration should be given to initiating therapy at lower than standard doses, with slow increases as tolerated in order to reach a therapeutic response.

Diet

Encourage a well-balanced diet. A healthy diet focuses on fruits, vegetables, whole grains, and low-fat or fat-free milk products and includes lean meats, poultry, fish, beans, eggs, and nuts. This type of diet is low in saturated fats, trans fats, cholesterol, salt (sodium), and added sugars. For more information see <http://www.cdc.gov/nutrition/index.html>.

Supplements

Ask the patient about use of alternative food or drug supplements and over the counter (OTC) products to determine safety, efficacy and possible negative interactions with prescribed medications and therapies. There have been no consistent data proving supplements are effective in treatment of CFS.

Activity

The majority of people with CFS are affected by postexertional malaise, which is defined as exacerbation of symptoms following physical or mental exertion, with symptoms typically worsening 12-48 hours after activity and lasting for days or even weeks. Postexertional malaise and exercise intolerance, though not unique to CFS, may help distinguish CFS from other disorders.

Some people with CFS inappropriately avoid all activity because personal experience has demonstrated a link between exertion and symptom expression and severity. An even greater number of people engage in an endless “push-crash” cycle of activity. It is important that emphasis be placed on balancing activity (preventing over- and under-activity) and stopping activity before illness and fatigue are exacerbated. Appropriate rest is a key element of the CFS management plan.

Partnering with the patient to develop a highly individualized activity plan is key to success. The health care practitioner can assist in identifying goals and setting realistic expectations. The primary objectives for the plan are to improve function and quality of life. Gear activities toward improving function in areas that are of greatest importance in achieving activities of daily living.

Graded Exercise Therapy

Graded activity and exercise is defined as starting from a very low, basic level of exercise and/or activity and gradually increasing it to a level where people can go about their daily life. *NOTE:* the level of activity may not be the same as before the CFS diagnosis. It is imperative that any CFS activity plan be started slowly and increased slowly. The pace should be agreeable to the patient. The patient will feel tired if they are exercising beyond their capacity. When beginning an activity program, some patients may only be able to exercise for as little as one minute. Avoid traditional aerobic-type exercise programs.

Simple stretching and strengthening exercise using only body weight for resistance is a good starting place for most people with CFS.

Cognitive Behavioral Therapy

A supportive counselor can help people cope with the anxiety, depression, grief, anger and guilt that often accompany any chronic illness. Cognitive behavioral therapy (CBT) has helped some patients develop realistic goals and effective coping mechanisms that contribute to better functioning. CBT aims to manage symptoms and illness-sustaining behaviors. It is used to manage many medical conditions.

Ongoing Care

Perhaps the most crucial role of the health care practitioner is to provide support and active follow-up, not only for the patient, but for family and significant others as well. Providers need to evaluate new symptoms for possible development of other illnesses and monitor any deterioration in function, tailoring the management plan accordingly.

Disability

By definition, all people with CFS are impaired. Impairment doesn't necessarily equal disability, and many patients are able to adapt to their current impediments by consulting with employers or rehabilitation specialists. The health care professional is a major source of documentation in the disability process. Keeping good clinical notes and using simple assessment tools to track health status are important to the process.

ADDITIONAL RESOURCES

A CFS toolkit for health care professionals, in-depth information on CFS patient care, complimentary self-study continuing education courses, and research findings are available at <http://www.cdc.gov/cfs>.

RECOGNITION AND MANAGEMENT OF CHRONIC FATIGUE SYNDROME

A RESOURCE GUIDE FOR
HEALTH CARE PROFESSIONALS



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

Visit <http://www.cdc.gov/cfs> for more in-depth information on patient care, research findings, and continuing education opportunities.

WHAT IS CFS?

Chronic fatigue syndrome (CFS) is an illness characterized by prolonged, debilitating fatigue and a characteristic group of accompanying symptoms, particularly problems with memory and concentration, unrefreshing sleep, muscle and joint pain, headache and recurrent sore throat. It is marked by a dramatic difference in pre- and post-illness activity level and stamina.

CFS shares various symptoms with many illnesses, including fibromyalgia, lupus, Lyme disease, sleep apnea, narcolepsy, untreated hypothyroidism, chronic hepatitis and depression.

Prevalence and Risk Factors

One to four million people in the United States are afflicted with CFS. Although CFS is most common in 40- to 60-year-old women, it is important to note that CFS can affect both sexes and all race, age and socioeconomic groups.

The majority of patients seen by health care professionals in private offices or clinics are Caucasian; however, studies suggest the highest rates may be in Latinos and African Americans. CFS has also been seen more commonly in adolescents than in younger children. Usually the precursor of CFS in adolescents is an infection (for example, mononucleosis) and most adolescents recover from CFS.

Prognosis

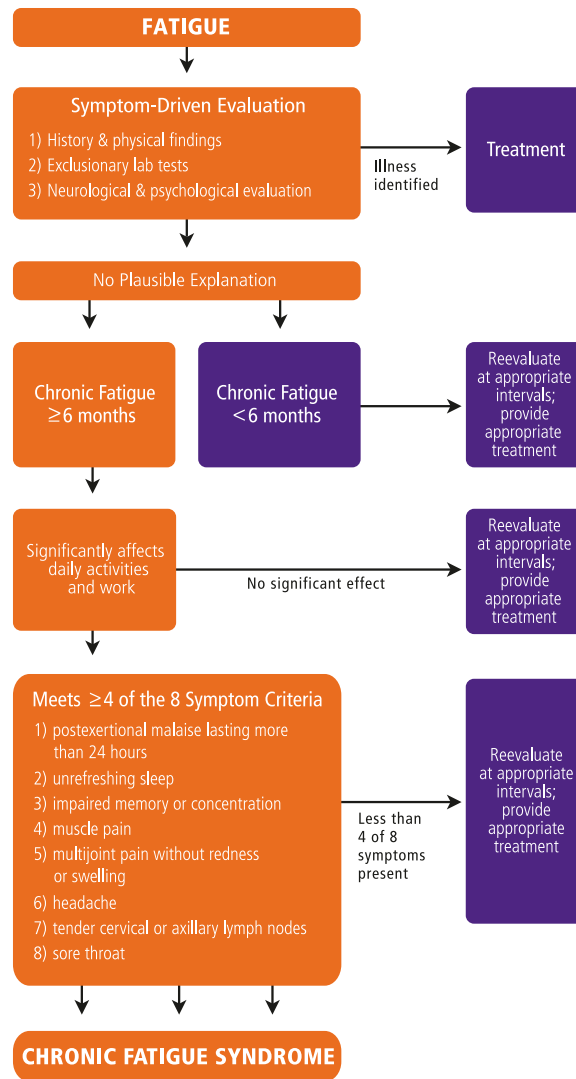
Long-term outcomes of CFS are not yet predictable in individual patients. It appears that many people with an acute onset, i.e., CFS following an infection, improve within two years, although they may continue to experience symptoms at a less debilitating level.

Individuals with a gradual onset may experience a prolonged course of illness, characterized by periods of remission and exacerbation. Symptom improvement, however, may occur even in people who have been ill for years.

Diagnosis

Despite two decades of research, CFS remains a clinical diagnosis without specific laboratory tests or markers. The process of sorting through symptoms and assessing abnormalities using a thorough history and physical exam is similar to the clinical assessment of any illness. CFS is considered to be a diagnosis of exclusion. The major difference is the more extensive exploration of the patient's subjective experience, i.e., patient symptom complaints and functional limitations. Physicians should listen carefully to how patients describe their symptoms and their social and physical environment. The goal of the healthcare provider is to identify all treatable conditions, and manage the patient's most bothersome symptoms; making a conclusive diagnosis of CFS is less critical.

CFS EVALUATION AND DIAGNOSIS MODEL



The 1994 Case Definition for evaluation and diagnosis of CFS, in the model shown above, guides the clinical diagnosis. If fewer than 4 of the 8 symptom criteria listed in the chart are present, the clinician should exercise judgment based on the course of illness, other symptoms and the patient's medical history.

HOW PHYSICIANS DIAGNOSE CFS

Step 1: Patient has 6 or more months of severe fatigue and symptoms like generalized pain and memory problems. Perform thorough medical history, physical exam, and mental status exam. If illness is identified, it should be treated. If not, go to Step 2. If a patient has CFS-like illness but less than 6 months of fatigue in duration, or has fewer than 4 symptoms, a similar management strategy to that of CFS can be followed while ruling out treatable conditions.

Step 2: Complete lab tests (listed in next section). If illness or condition is identified from lab results, illness should be treated. If not, go to Step 3.

Step 3: Diagnose patient with CFS if all criteria from the 1994 Case Definition are met. If previous illnesses from the physical exam or lab tests have been resolved and the patient meets criteria for CFS according to the 1994 Case Definition, diagnose with CFS.

HISTORY AND PHYSICAL EXAM

Patients need to be constantly re-evaluated in order to provide appropriate treatment even after a CFS diagnosis. The examination for the syndrome must include a routine neurological and psychological screening, a thorough physical exam and routine laboratory tests:

- Complete Blood Count (CBC) with leukocyte differential
- Erythrocyte sedimentation rate (ESR)
- Total protein
- C-reactive protein
- Alanine aminotransferase (ALT) or aspartate transaminase serum level (AST)
- Alkaline phosphatase (ALP)
- Blood urea nitrogen (BUN)
- Electrolytes
- Creatinine
- Albumin
- Globulin
- Glucose
- Calcium
- Phosphorus
- Thyroid function tests (TSH and Free T4)
- Urinalysis

Further tests may be indicated to confirm or exclude a diagnosis, which better explain the fatigue state (i.e., polysomnography for suspected sleep apnea) or which are suggested by results of the above screening tests.

Symptom Assessment

Evaluation of patients with unexplained chronic fatigue must include the frequency, severity and duration of accompanying symptoms. For symptom impact, patients are asked, "During the past week, how much have your symptoms interfered with your usual work, school, home or social activities?"