



# Chronic Fatigue Syndrome (CFS)

## Guide to Good Health

### *Healthy Living Guide*

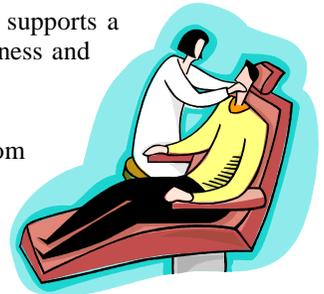
- ▶ Asthma
- ▶ Chronic Fatigue Syndrome (CFS)
- ▶ Chronic Obstructive Pulmonary Disease (COPD)
- ▶ Coronary Artery Disease (CAD)
- ▶ Depression
- ▶ Hyperlipidemia
- ▶ Hypertension
- ▶ Osteoarthritis (OA)
- ▶ Osteoporosis
- ▶ Type 2 Diabetes
- ▶ Back Pain
- ▶ Chronic Pain
- ▶ Healthy Eating
- ▶ Healthy Pregnancy
- ▶ Rheumatoid Arthritis (RA)
- ▶ Sleep
- ▶ Smoking Cessation
- ▶ Stress Management
- ▶ Weight Management
- ▶ Bariatric Surgery

## What is Chronic Fatigue Syndrome (CFS)?

Chronic fatigue syndrome is an illness characterized by profound, debilitating fatigue lasting at least six months that results in substantial reduction in occupational, personal, social, cognitive or educational activities.

### Overview & Facts

- ✓ **At least 1 million Americans have Chronic Fatigue Syndrome (CFS).** This illness strikes more Americans than multiple sclerosis, lupus, lung cancer or ovarian cancer.
- ✓ **Less than 20% of Americans with CFS have been diagnosed.** The low rate of diagnosis supports a need for increased CFS awareness among individuals experiencing the symptoms of the illness and among providers throughout the health care system.
- ✓ **CFS can be debilitating.**  
By definition, all CFS patients are functionally impaired. While symptom severity varies from patient to patient, Center for Disease Control (CDC) studies show that CFS can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease, chronic obstructive pulmonary disease (COPD) and similar chronic conditions.
- ✓ **CFS has a severe economic impact.** The annual economic impact of chronic fatigue syndrome in the United States is estimated to be \$9.1 billion in lost productivity, not including medical costs or disability payments. The average family affected by CFS loses \$20,000 a year in wages and earnings.



### Signs & Symptoms

- ✓ 4 or more of the following symptoms are present for 6 months or more:
  - Poor memory or concentration
  - "Postexertional malaise" (extreme, long periods of tiredness after long periods of physical or mental exertion)
  - Unrefreshing sleep (does not seem awake and alert after waking up from sleep)
  - Muscle pain
  - Pain in many joints without swelling or redness
  - Headaches that are of a different type of pain from before
  - Sore throats that are happening more often
  - Tender cervical or axillary lymph nodes
- ✓ Long periods of tiredness that is unexplained, this may not be due to movement, is not substantially relieved by rest, is new to you (not lifelong) and results in a significant reduction in previous levels of activity.



### Causes

**Infectious Agents:** Due in part to its similarity to acute or chronic infections, Chronic Fatigue Syndrome (CFS) was initially thought to be caused by a virus infection (i.e., Epstein-Barr (EBV) mononucleosis). It now seems clear that CFS is not caused exclusively by any single recognized infectious disease agent. Center for Disease Control's (CDC) four-city surveillance study found no association between CFS and infection by a wide variety of human pathogens, including EBV, human retroviruses, human herpesvirus 6, enteroviruses, rubella, *Candida albicans*, and more recently bornaviruses and *Mycoplasma*. Taken together, these studies suggest that among identified human pathogens, there appears to be no causal relationship for CFS as a whole.

However, the possibility remains that CFS may have multiple causes leading to a common endpoint, in which case some viruses or other infectious agents might have a contributory role for a subset of CFS cases.

**Hypothalamic-Pituitary Adrenal (HPA) Axis:** Many laboratory studies have suggested that the central nervous system (CNS) may have an important role in CFS. Physical or emotional stress, which is commonly reported as a pre-onset condition in CFS patients, activates the hypothalamic-pituitary-adrenal axis, or HPA axis, leading to increased release of cortisol and other hormones. Cortisol and corticotrophin-releasing hormone (CRH), which are also produced during the activation of the HPA axis, influence the immune system and many other body systems. They may also affect several aspects of behavior. Recent studies revealed that CFS patients often produce lower levels of cortisol than do healthy controls.

## *Causes continued*

Nutritional Deficiency (Shortage): There is no published scientific evidence that CFS is caused by a nutritional deficiency. Many patients do report intolerances for certain substances that may be found in foods or over-the-counter medications, such as alcohol or the artificial sweetener aspartame. While evidence is currently lacking for nutritional defects in CFS patients, it should also be added that a balanced diet can be conducive to better health in general and would be expected to have beneficial effects in any chronic illness.



Immunology (Immune System): T-cell activation markers have also been reported to have differential expression in groups of CFS patients compared with controls, but again, not all investigators have consistently observed these differences. One intriguing idea is that many triggering events, such as stress or a viral infection, may lead to the chronic expression of cytokines and then to CFS. Administration of some cytokines in therapeutic doses is known to cause fatigue, but no characteristic pattern of chronic cytokine secretion has ever been identified in CFS patients. In addition, some investigators have noted clinical improvement in patients with continued high levels of circulating cytokines; if a causal relationship exists between cytokines and CFS, it is likely to be complex. Finally, several studies have shown that CFS patients are more likely to have a history of allergies than are healthy controls. Allergy could be one predisposing factor for CFS, but it cannot be the only one, since not all CFS patients have it.

## *Risk Factors*

- CFS occurs four times more frequently in women than in men, although people of both sexes can develop the disease.
- The illness occurs most often in people aged 40-59, but people of all ages can get CFS.
- CFS is less common in children than in adults. Studies suggest that CFS is more prevalent in adolescents than in children under the age of 12.
- CFS occurs in all ethnic groups and races, and in countries around the world. In the United States CFS is at least as common among African Americans and Hispanics as it is among Caucasians.
- People of all income levels can develop CFS, although there is evidence that it is more common in lower-income than in affluent individuals.
- CFS is sometimes seen in members of the same family, but there is no evidence that it is contagious. Instead, there may be a familial predisposition (history) or a genetic link. Further research is needed to explore these possible relationships.



Neurally Mediated Hypotension (Low Blood Pressure): The investigators were alerted to this possibility when they noticed an overlap between their patients with CFS and those who had NMH. NMH can be induced by using tilt table testing, which involves laying the patient horizontally on a table and then tilting the table upright to 70 degrees for 45 minutes while monitoring blood pressure and heart rate. Persons with NMH will develop lowered blood pressure under these conditions, as well as other characteristic symptoms, such as lightheadedness, visual dimming, or a slow response to verbal stimuli. Many CFS patients experience lightheadedness or worsened fatigue when they stand for prolonged periods or when in warm places, such as in a hot shower. These conditions are also known to trigger NMH. One study observed that 96% of adults with a clinical diagnosis of CFS developed hypotension during tilt table testing, compared with 29% of healthy controls. Tilt table testing also provoked characteristic CFS symptoms in the patients.





## *Questions to Ask Your Provider*

1. Why am I having these symptoms?
2. What kind of tests do I need to have?
3. Describe all of what you are experiencing.
4. What can I do to make it better?

## *Diagnostic Workup*

Despite two decades of research, CFS remains a clinical diagnosis without specific laboratory tests or markers. The process the physician takes to sort through symptoms and assess abnormalities may take asking a thorough history and including an initial physical exam. This is similar to the clinical assessment of any illness.

The major difference is that the more extensive exploration the physician takes of the patient's own experience, i.e., patient symptom complaints and functional limitations, the more knowledge the physician has to make a better diagnosis to treat the condition.



## *Treatment and Care*

### **1. Medical**

- a. Symptomatic treatment - Treat symptoms which are most disruptive.
- b. Treating specific symptoms (e.g., sleep problems, muscle, joint pain, thinking problems, tiredness, headaches, sore throat, gastrointestinal complaints, depression and allergies) to name a few.

### **2. Pharmacological**

- a. Drug therapy is directed toward relief of specific symptoms experienced by individual patients.
- b. Many CFS patients are sensitive to medications, especially sedating medications.
- c. Some drugs act on multiple body systems and symptoms. For instance, tricyclic antidepressants may not only improve mood, but may help with sleep and pain. Prescribing such drugs allows the use of fewer medications to address multiple symptoms with minimal side effects.

### **3. Emotional/Psychological**

- a. Professional counseling - Consulting with a trained professional will help most patients to build effective coping skills. Help to cope with having a long-term illness.
- b. Cognitive Behavioral Counseling (CBT)
- c. Avoid mental extremes - exhaustion, stress

### **4. Physical**

- a. Develop an exercise program - start slowly and increase gradually.
- b. Set a realistic goal with severely ill patients. Focus on improving flexibility and minimizing the impact of deconditioning so they can increase function enough to manage daily activities.
- c. Alternate therapies - When traditional therapies do not work; including when traditional drug treatments do not provide enough symptom relief. May include: Hydrotherapy, Acupuncture, Massage, Deep Breathing, Relaxation therapy, Biofeedback, Yoga, and Tai Chi to name a few.
- d. Avoid physical extremes in exertion.
- e. Adopt good sleep habits.



## *Treatment and Care continued*

### 5. Nutritional

- a. Nutritional supplements and vitamins are frequently used by people with CFS for symptom relief. There have been few clinical trials on nutritional supplements and vitamins, these products are unregulated, and information on potency and side effects is frequently unknown. However, many CFS patients report symptom relief with use. Therefore, health care professional and patients need to talk about supplement use and OTC products to determine safety, effectiveness and possible negative interactions with prescribed medications and therapies.
- b. A balanced diet can be expected to have beneficial effects in any chronic illness.
- c. Avoid or reduce exposure if you are sensitive to the following: refined sugar, caffeine, alcohol, or tobacco.
- d. Nutritional supplements cannot take the place of good diet and nutrition.
- e. Avoid herbal remedies like comfrey, ephedra, kava, germander, chaparral, bitter orange, licorice root, yohimbe and any other supplements that are potentially dangerous.



## *Healthy Lifestyle Management*

### Physician Specialties that treat CFS

- Primary Care Providers
- Mental Health Professionals
- Rehabilitation Specialists and Physical Therapists
- Exercise Therapists
- Other Specialists, like a sleep therapist or dietician, can be added as needed, and you may need only one or two consultations with such specialists.



If you do not have access to these specialists or if your insurance doesn't cover such consultations, you can still work with your primary care professional to develop an effective treatment plan.

## *Resources*

- ❖ Centers for Disease Control and Prevention: <http://cdc.gov/>
  - ✓ CFS Awareness Campaign
  - ✓ CFS Treatment Options: Coping and Managing
  - ✓ CFS Basic Facts
  - ✓ CFS Toolkit for Health Care Professionals: Managing Supportive Care
  - ✓ CFS Toolkit for Health Care Professionals: Basic CFS Overview
  - ✓ CFS Toolkit for Health Care Professionals: Managing Symptoms
  - ✓ Understanding Chronic Fatigue Syndrome
  - ✓ CFS Toolkit for Health Care Professionals: Cognitive Behavioral Therapy
  - ✓ CFS Toolkit for Health Care Professionals: Managing Activity
  - ✓ CFS Toolkit for Health Care Professionals: Diagnosing CFS
- ❖ The Trans-NIH Working Group on Chronic Fatigue Syndrome: <http://orwh.od.nih.gov/cfs.html>