

CFS Toolkit for Health Care Professionals: Basic CFS Overview

WHAT'S IN THIS TOOLKIT?

Chronic fatigue syndrome, or CFS, is a debilitating and complex illness that can be challenging to diagnose and treat. These challenges often leave both patients and health care professionals locked in a cycle of frustration.

This CFS toolkit is designed to help break this cycle. It provides a quick and easy-to-use resource for clinical care. In less than 30 minutes, you can review the best practices related to diagnosing and managing CFS. You can also learn about other credible resources, ongoing CFS research and continuing education opportunities.

Whether you are a physician, nurse practitioner, physician assistant or other health care professional, you *can* help patients with CFS. You can assist patients in managing symptoms, improving function, conserving energy and monitoring activity levels. While there is still no cure for CFS, there *are* treatment options that help patients improve their quality of life and increase activities of daily living.

WHAT IS 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 or educational activities. The fatigue is not improved by rest, may be worsened by physical or mental activities, and is accompanied by characteristic symptoms. These symptoms include problems with memory and concentration, unrefreshing sleep, muscle and joint pain, headaches, tender cervical or axillary lymph nodes, recurrent sore throat and an increase in fatigue and in patient-specific symptoms persisting longer than 24 hours following mental or physical exertion.

The clinical course and symptom severity of CFS varies considerably among the patient population. There is frequently an intermittent pattern of relapse and remission. The illness is marked by a dramatic decline in activity level and stamina. People with CFS perform at a significantly lower level of activity than they were capable of prior to the onset of the illness.

As yet, there are no diagnostic tests or laboratory markers for CFS, and its pathophysiology is unknown.

WHY IS CFS A PUBLIC HEALTH CONCERN?

There are several reasons health professionals should be knowledgeable about CFS:

- **At least 1 million Americans have 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, 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.

WHO IS AT RISK FOR CFS?

Researchers continue to explore possible causes, risk factors and triggering factors for CFS. Many questions remain, but there are some characteristics that may help health care practitioners identify patients who are most at risk for CFS. The stereotype that CFS is an illness that primarily affects white, middle-class, well-educated, professional women is incorrect.

- 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 or a genetic link. Further research is needed to explore these possible relationships.

OVERCOMING OBSTACLES TO CLINICAL CARE

In several recent research studies funded by the CDC, common barriers to diagnosing and treating CFS were identified among primary care practitioners, including family practice physicians, internists, nurse practitioners and physician assistants. Overcoming these obstacles can increase diagnostic rates and improve therapeutic outcomes for CFS patients. The most common obstacles identified were:

- **Uncertainty about whether CFS is real.** After more than 3,000 research studies, there is now abundant scientific evidence that CFS is a real physiological illness. It is not a form of depression or hypochondriasis. A number of biologic abnormalities have been identified in people with CFS, but how they contribute to the illness is still unclear.
- **Uncertainty about how to diagnose CFS.** Although there is no laboratory test or marker to identify CFS, there is an international case definition for chronic fatigue syndrome that provides a reliable diagnostic algorithm.

- **Uncertainty or hesitancy about making a diagnosis that may contribute to the illness.** Validating a patient's illness experience may have therapeutic value and reduce the cycle of frustration between patients and their health care team. There is also evidence to suggest that the longer a person is ill before a diagnosis, the more complicated the course of the illness appears to be, making early detection and treatment of CFS of utmost importance.
- **Uncertainty about how to treat CFS.** Although managing CFS can be challenging, there are a number of therapeutic strategies that health professionals can use to tailor a multidimensional treatment program.

WHAT'S THE CLINICAL COURSE OF CFS?

CFS often follows a randomly cyclical course, alternating between periods of illness and relative well-being. The nature of the symptom complex often changes over time as well.

The percentage of patients who recover is unknown. Some patients recover completely with time. Others improve to the point that they can resume work and other activities, but continue to experience periodic CFS symptoms. Some patients grow progressively worse. Studies conducted by the CDC have found that 40-60% of people with CFS report partial or total recovery, but more research on the long-term course of the illness is needed to validate these findings.

There is some evidence to indicate that the sooner a patient is treated, the better the chance of improvement. This means delays in diagnosis and treatment could adversely affect therapeutic outcomes.