

Institute of Medicine committee releases report on ME/CFS; CDC archives CFS Toolkit

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.

Chronic Fatigue Syndrome

A Toolkit for Providers



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



Introduction to the Toolkit

Chronic fatigue syndrome (CFS) is a complex and serious illness. The CFS toolkit was prepared to provide a quick and easy-to-use resource for clinical care. It provides the best practices for diagnosing, treating and managing CFS. The approach may also be considered for people with CFS-like illnesses.

Healthcare professionals can use this toolkit to work with patients suffering from CFS by managing symptoms, improving function, conserving energy (for example, not becoming overtired), and monitoring activity levels. Even though there is no cure yet for CFS, there are treatment options that improve CFS patients' quality of life and increase daily living activities.



Diagnosis

Because there is no specific test to diagnose CFS, the diagnosis is made through clinical and laboratory examinations to exclude other conditions. A detailed patient history and thorough physical and mental status examination will help in making the diagnosis. A series of laboratory tests will help identify or rule out other possible causes of symptoms. A diagnosis of CFS-like illness could be made if a patient has been fatigued for 6 months or more, but does not meet the symptom criteria or the rest or activity criteria of fatigue for CFS.

A clinician should consider a diagnosis of CFS if these two criteria are met:

1. Unexplained, persistent fatigue present for 6 months or more that is not due to ongoing exertion; is not substantially relieved by rest, is of new onset (not lifelong) and results in a significant reduction in previous levels of activity
2. Four or more of the following symptoms are present for six months or more:
 - Impaired memory or concentration
 - Postexertional malaise (extreme, prolonged exhaustion and sickness following physical or mental activity)

- Unrefreshing sleep
- Muscle pain
- Multi-joint pain without swelling or redness
- Headaches of a new type or severity
- Sore throat that's frequent or recurring
- Tender cervical or axillary lymph nodes



How to Make a Diagnosis

In order to diagnose CFS, health practitioners must rule out medical and psychiatric conditions with similar symptoms by giving:

1. A detailed patient history
2. A thorough physical examination
3. Mental status screening
4. Laboratory screening tests

International CFS Case Definition (1994)

1. Severe chronic fatigue of 6 months or longer that is not explained by any medical or psychiatric diagnosis
2. Have 4 or more of the following 8 symptoms:
 - post-exertional malaise lasting more than 24 hours
 - unrefreshing sleep
 - significant impairment in short term memory or concentration
 - muscle pain
 - multi-joint pain without swelling or redness
 - sore throat
 - tender lymph nodes
 - headaches of a new type, pattern, or severity

Recommended laboratory screening tests

- CBC with differential
- Total protein
- Glucose
- C-reactive protein
- Phosphorus
- Electrolytes
- Alkaline phosphatase
- Creatinine
- Blood urea nitrogen (BUN)
- Albumin
- ANA and rheumatoid factor
- Globulin
- Calcium
- Alanine aminotransferase (ALT) or aspartate transaminase serum level (AST)
- Thyroid function tests (TSH and Free T4)
- Urinalysis

Illnesses that may resemble CFS

It is important for persons with symptoms of CFS to consult a physician. CFS symptoms resemble those of many treatable medical and psychiatric conditions. These include sleep disorders, depression, alcohol/substance abuse, diabetes, hypothyroidism, mononucleosis (mono), lupus, multiple sclerosis (MS), chronic hepatitis and various malignancies. Lab tests, medical history, and exams can help identify specific diseases.

If identified conditions are adequately treated and CFS symptoms continue, the patient could be considered to have CFS. This should not prevent continued medical monitoring of the patient.

CFS and other illnesses

People with CFS also are more likely to have obesity, insulin resistance, metabolic syndrome, irritable bowel disease, non-melancholic depression, fibromyalgia, chemical-sensitivity disorder; these conditions should be evaluated if the patient appears symptomatic. It is important for persons with CFS to continue to see their healthcare provider and report changes in symptoms. Sometimes a person diagnosed with CFS may have other symptoms which could be resolved with treatment.

Treatment and Management

Managing chronic fatigue syndrome can be as complex as the illness itself. There is no cure yet, no prescription drugs have been developed specifically for CFS, and symptoms vary considerably over time.

The management of CFS may require working with a team of doctors and other health care practitioners, which might include mental health professionals, rehabilitation specialists, and physical or exercise therapists, to create an individualized treatment program. This program should be based on a combination of therapies that address coping techniques, symptoms and activity management. If a team approach is not practical, primary care providers can address the individual's needs.



Rationale for Treatment and Management

Rationale for Management

- Treat other illnesses or conditions occurring at the same time as CFS or underlying medical/psychiatric conditions.
- Identify the most bothersome symptoms.
- Employ drug therapy to relieve symptoms.
- Empower the patient to be active in managing the illness.

Drug therapies

- Use as few medications as possible.
- Remember that supplements and over-the-counter drugs can interact with prescription drugs and cause side-effects, please remind CFS patients to consult with a clinician before taking any of these medications.
- Start with a small dose because many CFS patients are sensitive to medications.
- Narcotics are not indicated for management of CFS-associated pain.
- Medicine for pain or discomfort should be limited to acetaminophen, aspirin, or NSAIDS (nonsteroidal anti-inflammatory drugs).
- Do not routinely use sleep medications to treat sleep problems. Sleep medication should be prescribed based on patient's responses to a complete sleep history.
- Treat clinical depression only. People with CFS may show signs of depression, but not have depression. Prescribing drugs for depression when a person is not depressed may make symptoms worse.
- Use caution in prescribing/taking antidepressants. Some antidepressants may make individual CFS symptoms worse or cause side effects.
- While use of a multivitamin is generally recommended for people who do not have balanced diets, it is not beneficial to buy trendy, expensive vitamins that have no effect on fatigue or pain.
- Avoid unsafe herbal remedies like comfrey, ephedra, kava, germander, chaparral, bitter orange, licorice root, and yohimbe.

Non-drug therapies

- Consider complementary therapies like acupuncture, gentle massage, deep breathing, relaxation therapy, yoga, or tai chi to increase energy and decrease pain.
- Suggest stretching and light exercise before bed.
- Help patients cope with memory difficulties by suggesting the use of organizers and schedulers. Puzzles, word games, and card games are other options to help increase focus.



Coping Skills for CFS

Adjusting and coping with the realities of CFS are important to feeling healthier. There are three ways that a person with CFS can strengthen their coping skills with emotional and psychosocial issues:

- 1** A supportive counselor can help patients cope with the diagnosis of long term illness, as well as the anxiety, depression, grief, anger and guilt that often accompany chronic illness.
- 2** CFS support groups can serve as a positive resource and social outlet for people with CFS.
- 3** For those who have enough energy to work, they should find appropriate employment and live as independently as they can.

Because chronic illnesses like CFS impact the entire family, not just the patient, family education and counseling may be helpful in talking about changes in family dynamics related to living with CFS.



Emotional Issues and Coping Solutions

Emotional issues

In addition to routine CFS symptoms, people with CFS may face emotional issues besides their symptoms such as:

- Problems coping with variable and unpredictable symptoms
- Uncertainty about the future of their personal health
- Feeling guilty, abandoned, and lonely

The following life changes can result from having CFS:

- Loss of independence, livelihood, and financial security
- Changes in relationships with family and friends
- A decrease in stamina that interferes with activities of daily living
- Memory and concentration problems that seriously impact work or school performance

It is normal for people with CFS to feel overwhelmed. However, in order to feel better, people should seek support to work through their emotions.

Solutions

Adjusting and coping with the realities of CFS are important to feeling healthier. There are three ways that a person with CFS can strengthen their coping skills with emotional and psychosocial issues.

1. **Professional counseling.** Get professional counseling, which can help people with CFS cope with their illness. A counselor can help people address their feelings of anxiety, depression, grief, anger, and guilt with problem solving techniques, standard psychotherapy, and counseling methods. Combined medication and psychotherapy may be appropriate in some situations.
2. **Support Group.** CFS support groups can serve as a positive resource and social outlet for people with CFS. Support group members share tips and experiences for living with CFS. Going to group meeting can also get people with CFS out of the house and connected with others who understand their situation.
3. **Working/not working with a disability.** For those who have enough energy to work, they should find employment that is favorable to their condition and live as independently as they can.

For people with CFS who are severely impaired and unable to work, it is important for them to accept and cope with the fact that they are temporarily unable to work and must utilize disability benefits. Doctors can help these persons with CFS by keeping good notes and using simple assessment tools to track health status for documentation purposes.



Cognitive Behavioral Therapy (CBT)

Cognitive behavioral therapy, or CBT, is an individualized, structured, goal-oriented form of therapy often prescribed to help chronically ill patients cope with illness and develop behaviors and strategies that help improve symptoms.

CBT has been shown to be effective for some patients with CFS, but it must be paced, personalized, and tailored to the individual's level.



Using Cognitive Behavioral Therapy to Help CFS Patients

Cognitive behavioral therapy (CBT) aims to change symptoms and illness supporting behaviors.

- CBT is used for medical and psychological illnesses. It has also been used to help people recover from cardiovascular disease, sleep disorders, diabetes, cancer, and orthopedic injuries.
- CBT has been shown to be effective for some patients with CFS.
- CBT makes patients aware of the stressors that make symptoms worse.
- CBT is often combined with increased physical activity or gradual exercise therapy.
- Trained healthcare professionals, such as psychologists, nurses, physical therapists, occupational therapists, can all guide a person through CBT.
- CBT must be paced, personalized, and tailored to the individual's level.
- In order for CBT to be successful, people in CBT must take personal responsibility for change.
- If CBT is not covered by insurance, people with CFS can substitute a provider who is knowledgeable about CFS. This provider can lead CFS patients to understand how their behavior is impacting the illness, and set up activity and exercise programs that are useful.

Local mental health professional groups, physical and occupational therapists, or health care organizations can be contacted to find a certified cognitive therapist.

Graded Exercise Therapy (GET)

A person is shown in a yoga pose, sitting on the floor with legs crossed and hands clasped above their head. The person is wearing a dark long-sleeved top and light-colored pants. The background is a light orange color.

Graded exercise therapy (GET) has shown to be very helpful to some CFS patients. 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.

Activities need to be spread evenly throughout the day and should not make symptoms worse. If activities are not spread out, patients will “push” themselves too much and “crash”.



Avoiding the Push-Crash Cycle with Graded Exercise Therapy

Activity Pacing

Activity pacing is recommended for many people with CFS. Pacing refers to taking activities such as doing laundry or shopping, and breaking it into small manageable tasks with rest breaks in between. Activities should be spread evenly throughout the day and should not make symptoms worse. If activities or exercises are not spread out, a “push - crash” cycle will occur. “Push - crash” cycle is when a person does too much all at once, crashes, rests, starts to feel better and does too much once again.

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.

- People that have done no exercise or activity for a long period of time and feel very weak should only do a basic activity (ex: stretching, walking, or biking for a few minutes). They should not feel tired after the activity. If the activity does induce tiredness, it should be lessened.
- If any of the symptoms of CFS get worse after adding activity, people should return to the last level of activity where they felt comfortable.
- Lifting light weights and stretching can help some people with CFS feel better. People can start with using their body weight (for example, raising their arms) and gradually increase to wall push ups, modified chair dips, and toe raises. Strengthening activity should precede aerobic activity.
- Very ill people who are housebound or bedbound can start with working on picking up and grasping objects. Activity should be increased until the person can handle activities of daily living such as getting up, dressing, moving around the house and brushing teeth. Having CFS does not mean that a person should avoid these activities, but instead means they should go slowly when starting a new activity.
- The GET Guide 2008 by Chronic Fatigue Syndrome/ME Service at St. Bartholomew’s Hospital can be helpful in structuring your graded exercise plan.



CFS Sleep Issues

The majority of CFS patients experience some form of problems with sleep. Most CFS patients experience non-restorative sleep as compared to their pre-illness experience.

Health professionals can help people with CFS adopt good sleeping habits. Patients should be advised to practice standard sleep hygiene techniques:

- schedule regular sleep and wake times—try to get up at the same time everyday
- establish a regular bedtime routine, which may include a warm bath or shower, or listening to soothing music
- avoid napping during the day
- incorporate an extended wind-down period
- use the bedroom only for sleep and sex; not for other activities such as

watching TV, reading, or working on a computer

- control noise, light and temperature in the bedroom
- avoid caffeine within 6 hours of bedtime, and alcohol and tobacco within 2 hours of bedtime
- light exercise and stretching earlier in the day, at least four hours before bedtime, may also improve sleep.

When sleep hygiene is not successful, the use of pharmaceutical drugs may be indicated.



Sleep Therapy

The majority of CFS patients complain of some form of sleep-related symptoms. Sleep deprivation or disruption may cause or worsen other symptoms such as fatigue, memory problems, headaches and joint pain. Treating sleep problems should occur early in the CFS treatment program.

A doctor should set up a consult with a sleep specialist or schedule a sleep study if a person with CFS symptoms identifies problems consistent with:

- sleep apnea (pauses in breathing or shallow breaths while sleeping)
- restless leg syndrome (uncontrolled movements of the lower legs and “crawly” sensations in the calves)
- sleep phase abnormalities
- persistent/recurrent daytime sleeping
- If insurance or other matters prevent a consultation with a sleep specialist, patients should speak to their primary care physicians about sleep problems.
- People with CFS symptoms should practice good sleeping habits (also known as sleep hygiene).
- Medications can be considered in the absence of specific sleep disorders if sleep hygiene is not successful. A short-term trial of sedating antihistamines or over-the-counter sleep products may assist initiation of good sleep hygiene.
- If this approach is not beneficial, then a trial of a prescription sleep medicine in the smallest possible dose may be warranted. Sleep medication for such patients should only be prescribed pending a complete sleep history and evaluation by a sleep specialist.
- Long term use of hypnotics is not recommended by many sleep specialists.

Sleep Hygiene Tips

- Go to bed at the same time each night and rise at the same time each morning.
- Make sure your bedroom is a quiet, dark, and relaxing environment, which is neither too hot nor too cold.
- Make sure your bed is comfortable and use it only for sleeping and sex and not for other activities, such as reading, watching TV, or listening to music. Remove all TVs, computers, and other “gadgets” from the bedroom.
- Physical activity may help promote sleep, but not within a few hours of bedtime.
- Avoid large meals before bedtime.



Contact Information

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