

Managing Symptoms

GUIDELINES FOR CFS PATIENTS

Symptomatic treatment

People with CFS exhibit different primary symptoms. Symptom severity can also vary considerably. Primary symptoms may include sleep problems, postexertional malaise, muscle and joint pain, cognitive dysfunction, fatigue, headaches and sore throat. Gastrointestinal complaints, orthostatic instability, depression and allergies are also seen in many patients. CFS patients should see their health care professional for aggressive symptom management for these and other disruptive symptoms.

Pharmacologic therapy

Pharmacologic therapy is directed toward the relief of specific symptoms experienced by the individual patient. There are many over-the-counter and prescription drug therapies that can be used to treat sleep difficulties, cognitive problems, pain and other symptoms of CFS.

Many CFS patients are sensitive to medications, particularly sedating medications. Therapeutic benefits can often be achieved at lower than normal dosages, so your clinician may prescribe a fraction of the usual recommended dose to start and gradually increase as necessary and as tolerated.

All medications can cause side effects, which may lead to new symptoms or exacerbate existing symptoms, so it's important to routinely discuss all prescription drugs, OTC therapies and supplements you're taking with your doctor.

Nutritional and herbal supplements

Nutritional supplements and vitamins are frequently used by people with CFS for symptom relief. While there have been few clinical trials to support the use of particular supplements, two studies suggest that oral NADH, which is important for cellular production of energy, may be helpful for treating CFS. Methylcobalamin, a form of vitamin B-12, has also been studied and is among the supplements that have support from some clinicians. Essential fatty acids like fish oil, evening primrose oil and flaxseed oil may also provide benefit for some CFS patients.

Although many CFS patients report symptom relief with supplements, these products are unregulated, and information on potency and side effects is frequently unknown. Patients need to question their health care professional about supplement use and OTC products to determine safety, efficacy and possible negative interactions with prescribed medications and therapies.

Patients should avoid herbal remedies like comfrey, ephedra, kava, germander, chaparral, bitter orange, licorice root, yohimbe and any other supplements that are potentially dangerous.

Alternative therapies

Alternative therapies are often explored by CFS patients to relieve symptoms. Discuss such options with a health care professional to make sure they are safe and effective.

Acupuncture, aquatic therapy, gentle massage, meditation, deep breathing, biofeedback, yoga, tai chi and massage therapy have been found to help some patients and are often prescribed for CFS symptom management.

Sleep disturbances

The majority of CFS patients experience some form of sleep dysfunction. Common sleep complaints include difficulty falling asleep, hypersomnia, frequent awakening, intense and vivid dreaming, restless legs and nocturnal myoclonus. Most CFS patients experience nonrestorative sleep—a feeling of profound fatigue, achiness and mental “fogginess” that lasts one or more hours after rising.

Sleep deprivation or disruption may cause or exacerbate other symptoms such as fatigue, impaired cognition, headaches and joint pain.

It's important to adopt good sleep habits. Patients should practice standard sleep hygiene techniques: establish a regular bedtime routine; avoid napping during the day, incorporate an extended wind-down period; use the bed only for sleep and sex; schedule regular sleep and wake times; control noise, light and temperature; and avoid caffeine, alcohol and tobacco. Light exercise and stretching earlier in the day, at least 4 hours before bedtime, may also improve sleep.

When sleep hygiene isn't successful, the use of pharmaceuticals may be indicated. Your health care practitioner may consider simple antihistamines or over-the-counter sleep products. If this isn't beneficial, a prescription sleep medicine in the smallest possible dose may be prescribed.

Pain

CFS pain occurs both in muscles (sometimes described as “deep pain”) and joints. Patients may also experience headaches (typically pressure-like) and soreness of the skin to touch.

Most pain therapy begins with simple analgesics like acetaminophen, aspirin or NSAIDs. If these don't bring relief, moderate pain can be treated with a mild narcotic. It's generally wise to avoid narcotics because of their potentially addictive qualities, but long-acting narcotics may be necessary when conservative methods have proven inadequate and when pain is severe and unrelenting. Counseling for pain management techniques is advisable for patients with this kind of unremitting pain.

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Pain management should include nonpharmacological treatments and alternative therapies. Stretching and movement therapies, gentle massage, heat, toning exercises, hydrotherapy and relaxation techniques can be helpful for CFS care. Acupuncture, when administered by a qualified practitioner who is knowledgeable about CFS, can be particularly effective for pain management in some patients.

Orthostatic instability

Some patients with CFS may exhibit symptoms of orthostatic instability, in particular frequent dizziness and light-headedness. Treatments for orthostatic problems include volume expansion for CFS patients who don't have heart or blood vessel disease. If symptoms don't improve with increased fluid and salt intake, your clinician may prescribe medications that treat low blood volume, increase blood pressure or prevent blood from pooling in the legs.

Depression

Research shows that CFS is not a form of psychiatric illness or depression. However, many people with chronic illnesses, including those with CFS, may suffer from secondary depression as the patient makes the multiple adjustments to having a debilitating, chronic illness.

As many as half of CFS patients develop depression sometime during the course of the illness. Although treating depression can reduce anxiety and stress, it's not a cure for CFS.

Patients should use caution in taking antidepressants. Antidepressant drugs of various classes have side effects that may act on other CFS symptoms and/or cause side effects.

Cognitive problems

Memory and concentration complaints are two of the more distressing symptoms for people with CFS. Relaxation and meditation training and memory aids, such as organizers, schedulers and written resource manuals, can be helpful in addressing cognitive problems. Stimulating your mind with puzzles, word games, card games and other activities may also be beneficial.

Your clinician may refer you to behavioral health professionals to help you problem-solve and develop specific techniques for conducting activities of daily living that have become difficult.

Use caution in taking stimulants for cognitive problems. Mild stimulants may be helpful for some patients, but stronger stimulants can precipitate the push-crash cycle and cause relapse.