

Chronic fatigue syndrome:

What nurses need to know

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Abstract: Chronic fatigue syndrome (CFS) is a long-term, often misunderstood disorder that involves the nervous, immune, metabolic, endocrine, and digestive systems. This article describes the pathophysiology of CFS, signs and symptoms of CFS in adults, diagnostic criteria for CFS, and nursing considerations for patients with CFS.

Keywords: CFS, chronic fatigue immunity deficiency syndrome, chronic fatigue syndrome, ME/CFS, myalgic encephalomyelitis/chronic fatigue syndrome, postexertional malaise, postviral fatigue syndrome, systemic exertion intolerance disease



CHRONIC FATIGUE SYNDROME (CFS) is a long-term, often misunderstood disorder that affects multiple body systems. It is also referred to as myalgic encephalomyelitis or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), chronic fatigue immunity deficiency syndrome, systemic exertion intolerance disease, and postviral fatigue syndrome.¹⁻⁴

CFS affects more women than men and is more likely to strike in middle age, although it can occur at any age, including childhood.¹⁻⁴ According to the CDC, an estimated 836,000 to 2.5 million Americans experience CFS, but most have not been diagnosed.³ This article describes the pathophysiology of CFS, signs and symptoms of CFS in adults, diagnostic criteria, and nursing considerations for patients with CFS.

Pathophysiology

The pathophysiology of CFS, which is not well understood, involves the nervous, immune, metabolic, endocrine, and digestive systems.^{5,6} Studies have shown a dysregulation of several limbic-hypothalamic-pituitary-adrenal axes that affect levels of certain hormones such as cortisol. Spots in the brain's white matter, neuroinflammation, and increased levels of lactate have also been documented.⁵

Orthostatic hypotension and tachycardia are common, indicating autonomic nervous system involvement. However, even when BP and heart rate are normal, a significant decrease in cerebral blood flow has been shown.⁵

Immune system changes involve abnormal functioning of white blood cells and an increased number of cytokines.⁷ Metabolic studies show a decrease in the ability to produce or use energy on the cellular level.⁶ In healthy people, exercise typically makes energy metabolism more efficient. The opposite is true in CFS. Digestive pathophysiology includes abnormalities of the gut microbiome and gut inflammation.⁵

Some have proposed that the triggering of one final common pathway leads to the cascade of abnormalities. That trigger may be inflammation, but this has yet to be determined.⁸

Debilitating fatigue and other symptoms

The hallmark of CFS is debilitating fatigue that does not improve with rest and that cannot be explained by an underlying medical disorder.⁴ In some cases, onset is acute, following an infection such as Epstein-Barr virus, trauma such as a motor vehicle crash, or surgery.⁹ But in some patients, symptoms develop gradually over months or years.¹⁰ Because the disorder is complex, symptoms are nonspecific, and many healthcare professionals are not well educated about it. Consequently, CFS is often overlooked or misdiagnosed.³

In CFS, fatigue may be severe enough to prevent the patient from conducting normal daily activities or even getting out of bed. At least 25% of patients are house- or bedbound at some point during their illness. About 50% of those affected by CFS are able to return to work, either full- or part-time.⁷

A characteristic of fatigue associated with CFS is that it may flare up after even light physical, emotional, or cognitive effort, a phenomenon called *postexertional malaise (PEM)*. Often described by patients as a



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“crash,” PEM may be triggered by something as simple as taking a shower or doing laundry. Patients may be house- or bedbound during an episode of PEM and not recover for weeks or more.^{3,4}

The fatigue of CFS is not relieved by sleep due to disturbances in sleep rhythm or quantity. Consequently, many patients experience nighttime insomnia and daytime hypersomnia.¹¹ Other common signs and symptoms include orthostatic intolerance (a drop in BP or an increase in heart rate upon standing); cognitive impairment; light, sound, food, or chemical sensitivities; pharyngitis; arthralgia; tender lymph nodes; and headaches.⁴ Comorbidities such as fibromyalgia, Sjögren syndrome, postural tachycardia syndrome, and allergies may also be present.^{1,11,12} The severity of signs and symptoms varies among individuals and often

fluctuates throughout the day or even over the course of months or years.

Like patients with other chronic illnesses, patients with CFS may experience depression and anxiety as they deal with a chronic disease. However, it is important to note that CFS is a biological, not a psychological, illness.⁹

Diagnosis

CFS definitions have varied over the years. In 2015, the Institute of Medicine (now the National Academy of Medicine) proposed these diagnostic criteria:^{13,14}

- A substantial reduction or impairment in the ability to engage in preillness levels of activity that lasts for more than 6 months, is accompanied by profound, new-onset fatigue, is not the result of ongoing or unusual exertion, and is not substantially alleviated by rest.
- PEM.
- unrefreshing sleep.

In addition, cognitive impairment and/or orthostatic intolerance must be present.

Currently, no diagnostic tests are available to confirm the diagnosis. Standard lab tests are often normal and patients are frequently told that nothing is wrong.⁵ However, an investigational blood test for CFS was recently proven reliable in an initial study.¹⁵ After cells from healthy individuals and CFS patients were stressed with a salt, investigators measured their responses. They found a clear difference in the way CFS cells reacted compared with healthy cells and attained 100% accuracy in identifying CFS cells using this nanoelectronic assay test. Currently the researchers are working on studying this test in a larger cohort.¹⁵

Although no approved diagnostic biomarker for CFS is yet available, clinicians must still run standard diagnostic studies to rule out thyroid disorders, adrenal insufficiency,

multiple sclerosis, and other diseases.⁷ Diagnosis is that of exclusion and based on the patient's signs and symptoms.^{1,7}

Treatment

To date, no treatments for CFS have been proven effective in large randomized trials.¹ Graded exercise therapy (GET) and cognitive behavioral therapy (CBT) were once recommended. However, in 2017 the CDC and the Agency for Healthcare Research and Quality removed GET and CBT as recommended interventions. Antiviral drugs, antibiotics, and vitamins have been shown to be ineffective.⁷

On the brighter side, some studies of patients treated with hydrocortisone have shown positive results in the short term.¹¹ Pharmacotherapy with dextroamphetamine, nefazodone, acetyl-L-carnitine, rintatolimod, and immunoglobulin each produced some improvements, but they did not have the epidemiologic significance to become the gold standard for the pharmacologic treatment of CFS.¹¹

The main goal of treatment is helping patients improve their quality of life by symptom relief.² Sleep disruption and pain are usually addressed first and may require a sleep or pain specialist. Epsom salt soaks, acupuncture, massage, yoga, and activity management are nonpharmacologic therapies that may be recommended.^{1,4}

Patients should be encouraged to be as active as their energy allows, but they must follow activity with adequate rest to avoid relapses. It is important to note that what works for one patient with CFS may not work for another.

Nursing considerations

Nurses caring for patients with CFS should keep these points in mind:

- Patients may need additional assistance with activities of daily living

For more information

- **American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society.** Dedicated to serving the needs of patients and caregivers through support, advocacy, and education.
<https://ammes.org>
- **Centers for Disease Control and Prevention.** Myalgic encephalomyelitis/chronic fatigue syndrome.
www.cdc.gov/me-cfs/index.html
- **Centers for Disease Control and Prevention.** Myalgic encephalomyelitis/chronic fatigue syndrome. Information for healthcare providers.
www.cdc.gov/me-cfs/healthcare-providers/index.html
- **Emerge Australia.** Providing hope and help to people with myalgic encephalomyelitis/chronic fatigue syndrome.
<https://emerge.org.au>
- **Solve ME/CFS Initiative.** Leading the fight to cure ME/CFS.
<https://solvecfs.org>

and take more time to recover from surgery and other medical procedures as well as any kind of emotional or mental stress.

- Nurses should monitor patients for orthostatic intolerance and intervene appropriately; for example, by including standby assist with ambulation in the nursing plan of care.
- Given the lack of standardized conventional treatments, patients may use alternative practitioners and therapies. During medication reconciliation, nurses should specifically inquire about vitamins and other supplements to avoid potential interactions with prescribed medications.
- Remember that many patients with CFS do not look sick and have no outward sign of illness.¹⁶ This does not mean they are not experiencing symptoms. In severe cases, they may be more functionally impaired than those with heart failure, multiple sclerosis, or end-stage renal disease.⁴ These patients must not be dismissed because they “look” healthy.

Provide compassionate care

Dr. Elizabeth Unger, the chief of the CDC's Chronic Viral Diseases Branch, which includes the CFS

program, says the predominant concern she hears from patients and their families is the difficulty finding informed and compassionate healthcare providers.² CFS is rarely covered in medical or nursing school courses.^{1,3} Despite the disabling nature of the disease, many patients have been dismissed by healthcare providers who think they are malingering.⁹ It is important for nurses to be advocates and support patients with CFS by acknowledging the significant impact this disease has on their lives and validating their experience and concerns. Both patients and healthcare providers can benefit by reviewing the CDC website and other resources (see *For more information*).

Hope for the future

Initially, CFS research lagged due to misunderstanding surrounding the disease.¹⁷ However, the National Institutes of Health has increased its research efforts in recent years.⁵ Soon, we may have a readily available biomarker, a better understanding of the pathophysiology, and a treatment for this debilitating disease. For now, healthcare professionals must support patients by educating themselves about CFS

and remembering that this is a real disease that has a significant and ongoing impact on patients' lives. ■

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