IN CASE OF EMERGENCY

IN CASE OF EMERGENCY

About me

Name

Address

Phone

Emergency contact

Name (relationship)

Address

Phone

IMPORTANT!!

□□ **Dogs and cats at home alone.** □□

Please call (emergency contact) to arrange care.

ALLERGIC TO (SUBSTANCE)

D.O.B.

Blood type:

Registered organ donor

GP

Name
Clinic
Phone

Other Physician

Name
Clinic
Phone

Relevant diagnoses:

- **Myalgic Encephalomyelitis** (ME/CFS, post viral disease), since YEAR
- Other permanent diagnoses

Transient diagnosis:

- Anything going on, expected to be resolved one day

Other diagnoses:

- Other stuff that might be relevant (e.g. hearing loss, Ehler-Danlos Syndrome)

Medications:

- **Name** dose (what it's for)

Supplements:

- **Name** dose (what it's for)

Other therapeutic supports:

Oxygen concentrator when sleeping

Note:

things like dentures, implants, pacemakers.

Diet:

Any dietary restrictions / preferences

How to help me

- (Vary to suit your needs)
- IV fluids, especially when blood pressure and/or blood oxygen levels are low (see ER & Urgent Care section)
- Pain relief if fibromyalgia is bad
- Keep me warm (seriously warm)
- Rest (low light / noise environment)
- Allow for (other illnesses you may have)
- Please trust me and listen to me: I know my illness, I know what is normal for me, and what is unusual and concerning. You can double-check things with my GP if needed.

ME/CFS crashes (flares) causes dysautonomia (parasympathetic nervous system disregulation). Symptoms in me may include any or all of:

- (Vary to suit your needs)
- Communication and cognitive difficulties
- Confusion
- Fibromyalgia (intense pain)
- Shallow / slow breathing
- Low blood oxygen levels
- Low blood pressure
- Difficulty swallowing
- Temperature disregulation, inability to stay warm – I feel really cold
- Lightheadedness / fainting
- Extreme fatigue
- Sound sensitivity
- Coughing
- Nausea
- Gastroparesis (slow stomach emptying)
- Reduced bowel motility

ER and Urgent Care

From the Bateman Horne Center handout:

Medical considerations when treating urgently ill patients with underlying myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

The intention of this handout is to provide basic advice and medical/scientific information about ME/CFS that can inform medical decisions in urgent, emergent, or hospital settings. Each page builds upon the next and has been separated for ease of review.

ME/CFS is a chronic, multisystem illness whose presence may impact decisions regarding diagnostic studies and medical interventions.

ME/CFS is characterized by severe fatigue and easy fatigability for both physical and cognitive tasks propagated by low energy reserves and pathologically altered metabolism.

Symptoms can worsen after physical, cognitive and emotional effort, as well as orthostatic, environmental, and sensory stress. **When subjected to these stressors, patients may experience a flare of exhaustion, cognitive impairment, pain and sensory amplification, headaches, autonomic dysregulation, dizziness, flu-like symptoms, or even non-epileptic seizures related to diffuse cerebral hypoperfusion.**

Common comorbid conditions in ME/CFS that may be responsible for flares or driving presenting symptoms include:

- Mast cell activation syndrome
- Small fiber polyneuropathies
- Postural orthostatic tachycardia syndrome (POTS)
- Gastrointestinal dysautonomia and functional GI dysmotility
- Pain amplification disorders (to include fibromyalgia)
- Multiple chemical or sensory sensitivities
- Primary sleep disorders
- Small intestine bacterial overgrowth (SIBO)
- Cranio-cervical instability
- Hypermobile Ehlers's Danlos syndrome
- Sicca syndrome
- Celiac disease
- Autoimmune thyroid disease, euthyroid sick syndrome

QUICK TIPS for managing patients with ME/CFS who become acutely ill

Presume the patient is orthostatic and treat as if in "hypovolemic shock" (abnormal perfusion and circulatory failure)

- Increase and maintain intravascular volume with IV saline (even when peripheral edema is present, as this is often 2/2 venous preload failure with secondary peripheral third spacing). Monitor orthostatic vital signs. Monitor and replace electrolytes. Consider alternating NS and LR. Avoid hypotension and hypovolemia. Albumin is not required in most instances.
- Provide oxygen even if not severely hypoxemic. SpO2 levels could be falsely depressed as a function of poor peripheral circulation (such as is seen with Raynaud's).
- Allow patients to lie down, or sit with feet elevated, limit activity and rest as needed. Avoid prolonged standing, or even sitting with feet on the floor. Provide a wheelchair for energy conservation when mobilizing.

Reduce sensory stimuli (sensory stress) as much as possible

- Reduce: bright light, loud music, obnoxious sounds, scents/odors.
- Maintain adequate pain control.
- Limit nighttime sleep disruptions, such as laboratory testing. Treat sleep, if needed and appropriate. Serial nights of sleep disruption may worsen ALL aspects of illness.

Assume waxing and waning cognitive impairment (cognitive slowing) is present

- Keep conversation simple. Avoid compound questions.
- Be patient and allow longer periods for patient responses to questions. Word-finding difficulties are common.
- Write down instructions.
- Allow family and caregivers to aid with communication.

Use medications thoughtfully and skillfully with close monitoring

- Patients with ME/CFS may be unusually sensitive to medication effects and more likely to have intolerances or allergic reactions. Medication side effects may be related to an exaggerated sympathetic nervous system response to foreign substances and not reflect known pharmacological side effects of medications.
- Start low (10 - 25% of usual) with medication doses. Consider past intolerances and experiences.
- Be cautious about abruptly stopping benzodiazepines and opioids, as the withdrawal can be amplified and dramatically provoke rebound symptoms.
- Consider "stress doses" of hydrocortisone (5-10 mg bid) as though the patient has adrenal insufficiency. Though cortisol levels may be normal, cellular response to normal cortisol levels is often downregulated.

The current evidence-based core clinical diagnostic criteria for ME/CFS (symptoms must be moderate to severe and present 50% of the time for at least 6 months) are: impaired ability to function in association with fatigue, post-exertional illness worsening, disordered sleep, cognitive impairment and/or orthostatic intolerance. Most patients also experience pain and immune manifestations.
https://pubmed.ncbi.nlm.nih.gov/25695122/

Based on current evidence the underlying pathology of ME/CFS involves energy metabolism, the nervous system, and the immune system.

Abnormal cellular metabolism. Metabolomics have found deficits in pathways that generate energy from simple sugars, fatty acids, and amino acids. Increased lactate levels in cerebrospinal fluid may indicate impaired oxidative phosphorylation, with a consequent shift to anaerobic metabolism. Cardiopulmonary exercise testing (CPET) testing suggests a low anaerobic threshold. Invasively monitored CPET demonstrates impaired/reduced pre-load and reduced oxygen extraction from either perfusion abnormalities or inability of cells to utilize delivered oxygen.

Neuroinflammation and central sensitization. Amplification of, or increased sensitivity to, sensory stimuli. Spinal fluid studies have shown elevated WBC and protein. MRI, functional MRI, and PET studies have revealed hypoperfusion, elevated lactate, and widespread activation of glial cells and astrocytes. EEG studies show abnormal brain waves and connectivity of various brain regions.

Cognitive impairment. High quality evidence supports cognitive slowing, deficits in attention, memory, and reaction time. It is unclear how much this relates to a neuroinflammatory process versus impaired brain perfusion.

Impaired/dysregulated HPA-axis and ANS stress response. Orthostatic intolerance is common. Neuroendocrine studies demonstrate abnormalities of the hypothalamic-pituitary-adrenal axis, of growth hormone secretion, and central signaling of cortisol release. ANS studies have found strong evidence of disordered autonomic nervous system activity, impaired baroreflex function, exaggerated venous pooling, diminished red cell mass, and reduced plasma volume.

Abnormal immune function. Evidence supports impaired natural killer cell function, increased numbers of activated CD8+ cytotoxic T cells, presence of various autoantibodies, particularly to targets in the CNS and ANS. Increased production of various proinflammatory cytokines correlate with illness severity. Mast cell activation is present in many patients.

Risk of viral reactivation (for example: varicella zoster, CMV, EBV, COVID-19, enteroviruses) may be present.

This handout was prepared in Jan. 2022 by Lucinda Bateman, MD, and Brayden Yellman, MD, of the Bateman Horne Center. It is intended to raise awareness about known aspects of ME/CFS. The tips are from Dr. Bateman and Yellman, experts in the management of ME/CFS. There are currently no treatment guidelines for ME/CFS, although expert consensus guidance has been published ***(2). Every case should be carefully assessed and treated using the best judgement of the managing physician, and for each presenting medical problem, taking current scientific progress and guidance into account.***

RESOURCES:

Inflammation correlates with symptoms in chronic fatigue syndrome. Komaroff AL. Proc Natl Acad Sci USA. 2017 Aug 22; 114(34): 8914-8916. Published online 2017 Aug 15 . doi: 10 .1073 / pnas.1712475114 PM CID: PMC5576849

ME/CFS: Essentials of Diagnosis and Management. Bateman L, et al. Mayo Clinic Proc. 2021 Nov 01. Vol 96, Issue 11, P2861-78.
DOI: https://doi.org/10.1016/j.mayocp.2021.07.004. Open Access

Batemanhornecenter.org   January 19, 2022

More information

An article for Nurses
About ME/CFS
What the CDC says

An article for Nurses

50 I Nursing2020 I Volume 50, Number 4

Chronic fatigue syndrome:

What nurses need to know

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 "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 and take more time to recover from surgery and other medical procedures as well as any kind of emotionalor 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.

(see original article for references and further information links. DOI-10.1097/01.NURSE.0000657068.67389.47)

ME/CFS Severity levels

Mild: Mobile and able to self-care. May be working or attending school, but often with accommodations and by reducing other domestic and social activities.

Moderate: Reduced mobility and restricted activities of daily living. Requires frequent rest periods and typically not working or attending school.

Severe: Mostly homebound. Limited activities of daily living (e.g., self-care, showering, dressing). Severe cognitive difficulties. May be wheelchair dependent.

Very Severe: Bedbound. Unable to carry out most activities of daily living for themselves. Often extreme sensory sensitivity to light, sound, touch, etc. May need total care.

These are general categories intended to convey the wide spectrum of disease severity and functional impairment seen in ME/CFS. The assessment of a given patient should be based on their particular level of disease severity and functional impairment.

PENE / PEM

PENE: Post-exertional Neuroimmune Exhaustion.

Also known as PEM: Post-extertional Malaise.

(PENE) is a **compulsory** neuroimmune symptom in the International Consensus Criteria diagnostic criteria for Myalgic Encephalomyelitis.

This cardinal feature is a **pathological inability to produce sufficient energy on demand** with **prominent symptoms primarily in the neuroimmune regions. Characteristics are:**

- **Marked, rapid physical and/or cognitive fatigability in response to exertion**, which may be minimal such as activities of daily living or simple mental tasks, can be debilitating and cause a relapse.
- **Post-exertional symptom exacerbation: *e.g.*** acute flu-like symptoms, pain and worsening of other symptoms.
- **Post-exertional exhaustion may occur immediately after activity or be delayed by hours or days.**
- **Recovery period is prolonged, usually taking 24 hours or longer.** A relapse can last days, weeks or longer.
- **Low threshold of physical and mental fatigability** (lack of stamina) results in a substantial reduction in pre-illness activity level.

https://me-pedia.org/wiki/List_of_symptoms_in_ME_CFS/ICC/PENE

Known common symptoms

Core symptoms

- profound fatigue, and
- decrease in function, and
- last at least 6 months, and
- exertional malaise (PEM), and
- unrefreshing sleep, and

either

- cognitive impairment

or

- orthostatic intolerance (OI)

Cognitive

- difficulties processing information
- concentration problems
- confusion
- difficulties with word retrieval
- word mix-ups
- short-term memory difficulties
- slowness in cognitive processes

Motor (movement) and balance

- muscle weakness or paralysis
- poor balance, ataxia & tandem gait
- clumsiness & tendency to drop things
- difficulty in tandem gait
- atypical numbness or tingling

Sleep disruption

- sleep disturbance - hypersomnia or insomnia
- non-refreshing sleep

Visual and auditory

- photophobia
- visual changes or eye pain
- double, blurred or wavy vision
- dry or itchy eyes
- tinnitus - buzzing or ringing in ears
- hyperacusis & cocktail party phenomena

Neuropsychological

- emotional flattening or personality change
- loss of adaptability
- anxiety &/or panic attacks
- reactive depression
- worsening of symptoms with stress

Immune system
- new sensitivities to medications, chemicals
- tender lymph nodes
- recurrent sore throat
- recurrent flu-like symptoms

Reproductive
- dysmenorrhea
- PMS or irregular menstrual cycles
- loss of sexual libido or impotence

Respiratory (breathing)
- exertional dyspnea (short of breath)
- sinusitis
- cough & wheezing

Urinary
- urinary frequency, bladder dysfunction

Circulatory
- neurally mediated hypotension
- postural orthostatic tachycardia syndrome (POTS)
- delayed orthostatic hypotension
- dizziness/light-headedness
- heart palpitations
- fluid retention
- extreme pallor
- bruising

Digestive
- lump in throat
- nausea
- heartburn
- abdominal pain
- irritable bowel syndrome

Neuroendocrine
- loss of thermostatic stability - low body temperature or diurnal fluctuations
- hot flushes
- excessive sweating or night sweats
- feelings of feverishness
- feelings of cold extremities
- heat/cold intolerance
- anorexia or abnormal appetite
- marked weight loss or gain
- hair loss

Musculoskeletal
- pain in muscles (myalgia)
- muscle cramps, particularly in legs
- chest pain and pressure
- pain in multiple joints (arthalgia)
- TMJ

Neurological (nervous system)

- persistent fatigue
- lack of endurance
- migraines or new onset headaches
- seizure-like phenomena

Sensory

- hypersensitivity to pain
- hyper-responsiveness to noxious stimuli
- perceptual & dimensional distortions
- feeling of burning or swelling
- overload phenomena
- loss of cognitive map
- Altered sense of taste and/or smell

https://me-pedia.org/wiki/List_of_symptoms_in_ME_CFS

Myalgic Encephalawhatnow??

The following extracts were shamelessly taken from the CDC handouts for healthcare providers.
https://www.cdc.gov/me-cfs/

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a **complex, chronic, debilitating disease** with systemic effects. ME/CFS is characterized by reduced ability to perform pre-illness activities that lasts for more than 6 months and is accompanied by profound fatigue, which is not improved by rest. A hallmark of ME/CFS is that symptoms can worsen after physical, mental, or emotional effort, a manifestation known as **post-exertional malaise (PEM)***. Patients with ME/CFS also have **unrefreshing sleep**. Other common manifestations are **orthostatic intolerance, cognitive impairment,** and **pain**. As can be observed in people with other long-term chronic illnesses, secondary psychological symptoms such as depression and anxiety may also be present in some patients with ME/CFS.

**Also known as PENE: Post-exertional Neuroimmune Exhaustion*

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a **complex, chronic, debilitating disease associated with multiple pathophysiological changes that affect multiple systems.**

EPIDEMIOLOGY

ME/CFS affects between 836,000 and 2.6 million Americans** of all ages, ethnicities, races, and socioeconomic groups. While ME/CFS can affect anyone, it affects women more than men. It is most common in people between 40 and 60 years old, but children and adolescents may also be affected.

CAUSES

While the cause of the disease remains unknown, **onset may follow an "infectious-like" syndrome** (e.g., fever, malaise, aching muscles, respiratory or gastrointestinal symptoms) or a well-documented specific infection (e.g., acute infectious mononucleosis).

*** An estimated 250,000 Australians have it.*

DIAGNOSIS

Diagnosis relies on a detailed medical and social history, physical exams, laboratory tests, and evaluation of other conditions that may resemble ME/CFS or be present as comorbidities.

ME/CFS diagnosis requires **all three symptoms occur at least half of the time with moderate, substantial, or severe intensity:**

- **Profound fatigue and impairment** that lasts more than six months
- **Post-exertional malaise (PEM)**
- **Unrefreshing sleep**

In addition, **at least one** of the following symptoms must be present:

- Impaired memory or ability to concentrate
- Orthostatic intolerance

DISEASE COURSE

Disease onset can be either gradual or sudden, and the course can be unpredictable and varies by individual. Some people may appear healthy and "normal" if they are not experiencing symptoms at the time of their clinic visit. However, most patients report that everyday activities such as doctor visits or grocery shopping can worsen their symptoms. ME/CFS can become so severe that some people need total care. About a quarter are bedbound; many are unable to work or go to school.

MANAGEMENT

Currently, there are no medications approved specifically for the treatment of ME/CFS. However, **healthcare providers can treat the symptoms and comorbid conditions.** Techniques to help patients cope with the disease can also improve their quality of life.

What Are ME/CFS Symptoms?

Three primary symptoms **ALWAYS** occur with ME/CFS. These must be of at least moderate intensity and be present at least 50% of the time to diagnose a patient with ME/CFS:

A substantial reduction or impairment in the ability to engage in pre-illness levels of activity (occupational, educational, social, or personal life) that:

- Lingers for more than 6 months
- Is accompanied by fatigue that is:
    - Often profound
    - Of new onset (not life-long)
    - Not the result of ongoing or unusual or excessive exertion
    - Not substantially alleviated by rest

Post-exertional malaise (PEM), an abnormal response to physical or cognitive exertion that:

- Is characterized by an exacerbation of some or all of a patient's symptoms (such as physical fatigue, cognitive problems, unrefreshing sleep, muscle or joint pain, light-headedness, sensory sensitivities, and flu-like symptoms) and a further loss of functional capacity

● Has either immediate onset, or onset delayed for hours or days after the exertion ● Has severity and duration of symptoms that are out of proportion to the inciting event. ● Takes days, weeks, or months to return to the pre-PEM baseline health For some patients, basic activities of daily living can trigger PEM, and PEM can affect a person’s ability to perform these activities or to attend school or work. The trigger varies between individuals and within the same individual at different points during their illness. These characteristics of PEM often make life difficult and unpredictable. **Unrefreshing sleep.** People with ME/CFS may not feel better or less tired even after a full night of uninterrupted sleep. Some may also have sleep disorders, including sleep apnea, that would benefit from treatment.	In addition, **at least one of the following two manifestations** must be present: ● **Cognitive impairment.** Most people with ME/CFS have problems with thinking, memory, executive function, and information processing as well as attention deficit and impaired psychomotor functions. All are exacerbated by exertion, effort, or stress, and may have serious consequences on a person’s ability to maintain a job, attend school, or engage in other activities of daily living. Patients often say they have “brain fog” to describe this problem because they are unable to think clearly. ● **Orthostatic intolerance.** People with ME/CFS develop a worsening of symptoms upon assuming and maintaining upright posture as measured by objective heart rate and blood pressure abnormalities during standing, bedside orthostatic vital signs, or head-up tilt testing. Orthostatic symptoms such as lightheadedness, fainting, increased fatigue, cognition, headaches, or nausea worsen with upright posture (standing or sitting) and improve (though not necessarily fully resolve) with lying down. This is often the most problematic manifestation of ME/CFS among adolescents.

OTHER COMMON SYMPTOMS

- Muscle pain
- Pain in the joints without swelling or redness
- Headaches of a new type, pattern, or severity
- Swollen or tender lymph nodes in the neck or armpit
- A sore throat that is frequent or recurring
- Gastrointestinal symptoms
- Genitourinary symptoms
- Sensitivity to light, sound, touch, and smell
- Chills and night sweats
- Visual disturbances
- Nausea
- Allergies or sensitivities to foods, odors, chemicals, or medications

Managing Post-Exertional Malaise (PEM) in ME/CFS

Helping patients manage PEM should be one of the first actions healthcare providers take. One of the best options to minimize or prevent PEM is to help patients learn to keep all energy expenditures, physical, cognitive and emotional, within limits that can be tolerated by planning when and how to use their limited energy. This approach is known as pacing. Minimizing PEM can lead to stabilization or improvements in pain, sleep, fatigue, cognition, and other symptoms. It can also prevent worsening of these symptoms. Activity pacing may improve quality of life considerably and even increase function.

Best practice: prevent harm! In the past, patients have been advised to be more active without any precautions about PEM. However, studies have demonstrated a lowered anaerobic threshold in patients with ME/CFS, suggesting impaired aerobic energy metabolism. **Increased activity can thus be harmful if it leads to PEM.** For some patients, even activities of daily living can trigger PEM. Any recommendation for increased activity or movement should take into account the patient’s energy limits (i.e., the “energy envelope”) and must be specific regarding the intensity, duration, frequency, and type of activity, especially for patients who are severely ill or experience orthostatic intolerance when upright.

Inactivity can result in muscle deconditioning. Providers should individualize **a threshold level of activity for each patient**. The challenge is to not overdo it and learn to adjust to less activity than before (e.g., going from easily walking a few miles to struggling to climb a flight of stairs). Some people use heart rate monitors to avoid going over the anaerobic threshold and activity monitors to avoid overexertion.

More on PENE / PEM (this cannot be stressed enough):

Post-exertional malaise (PEM) is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks. PEM can be mitigated by activity management (pacing). The goal is to avoid PEM flare-ups and illness relapses by balancing rest and activity.

Patients need to **determine their individual limits for mental and physical activity,** and plan activity and rest to stay within these limits. Some patients and healthcare providers refer to staying within these limits as staying within the "**energy envelope.**" Limitations may be different for each patient. Keeping individual activity and symptom diaries may be helpful to patients in identifying their personal limitations, especially early on in clinical care. Healthcare providers need to keep in mind that when patients with ME/CFS exceed their individual capacities, PEM and serious deterioration of function may result. In general, patients should not push themselves beyond their capacities as this may exacerbate the symptoms and trigger PEM. When patients experience improvement, activities can be cautiously increased

with monitoring for any negative effects. Patients need to be advised about “push and crash” cycles: patients sometimes respond to having a “good day” by subsequently doing too much to make up for “lost time,” and then relapsing. Any activity or exercise plan for people with ME/CFS needs to be carefully designed based on individual presentation with input from each patient. If possible, evaluation by a rehabilitation specialist may be beneficial. For some patients, even daily chores and activities such as cleaning, preparing a meal, or taking a shower can be difficult and may need to be broken down into shorter, less strenuous pieces. While vigorous aerobic exercise can be beneficial for many chronic illnesses, **patients with ME/CFS do not tolerate such exercise routines**. Standard exercise recommendations for healthy people can be harmful to patients with ME/CFS.	