

CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome

Goals and Objectives

Course Description

“Chronic Fatigue Syndrome” is an asynchronous online continuing education course for physical therapists and physical therapist assistants. This course presents updated information about Chronic Fatigue Syndrome including sections on etiology, symptomology, diagnosis, assessment, therapeutic intervention, prognosis, and disability.

Course Rationale

The purpose of this course is to present physical therapists and physical therapist assistants with current information about Chronic Fatigue Syndrome. A greater understanding of Chronic Fatigue Syndrome will enable physical therapists and physical therapist assistants to provide more effective and efficient rehabilitative care to individuals affected by this condition.

Course Goals and Objectives

Upon completion of this course, the participants will be able to:

1. Identify individuals most susceptible to CFS
2. List the many possible causes of CFS.
3. Differentiate between each of the proposed CFS case definitions utilized over the last 20 years.
4. Define the evaluative process and diagnostic model utilized to establish a diagnosis of CFS
5. Define the clinical course of CFS.
6. Identify common symptomology of CFS.
7. Identify other physical, psychological, and social issues associated with CFS.
8. Define rehabilitative goals for individuals with CFS.
9. Outline a therapeutic intervention plan to achieve rehabilitative goals.
10. Define an effective exercise program for individuals with CFS.
11. Identify the principles of cognitive behavioral therapy.
12. Identify additional therapies available to individuals with CFS.

Course Provider – Innovative Educational Services

Course Instructor - Michael Niss, DPT

Target Audience – physical therapists and physical therapist assistants

Course Educational Level – Introductory / intermediate

Course Prerequisites – None

Method of Instruction/Availability –Online text-based course available continuously.

Criteria for Issuance of CE Credits - A score of 70% or greater on the course post-test.

Continuing Education Credits- 4 hours

Fees - \$39.95

Conflict of Interest – No conflict of interest exists for the presenter or provider of this course.

Refund Policy - Unrestricted 100% refund upon request. The request for a refund by the learner shall be honored in full without penalty or other consideration of any kind. The request for a refund may be made by the learner at any time without limitations before, during, or after course participation.

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Chronic Fatigue Syndrome Course Outline

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Overview

Chronic fatigue syndrome (CFS) is a complex illness characterized by profound fatigue of at least six months' duration 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 (impaired memory or concentration, unrefreshing sleep, headaches, muscle pain, joint pain, sore throat and tender cervical/axillary nodes). CFS is marked by a dramatic difference in pre- and post-illness activity level and stamina.

Most people with CFS who consult health care professionals describe their illness as beginning suddenly over a period of hours or days. In contrast, most people with CFS who are identified in community studies describe a gradual onset of illness over weeks or months. The clinical course of CFS varies considerably among people with the condition and frequently has an intermittent pattern of relapse and remission. As yet, there are no diagnostic tests or laboratory markers for CFS, and its pathophysiology remains unknown.

Illnesses similar to CFS have been documented for several centuries, some possibly linked to bacterial, viral or protozoal infections such as brucellosis, yellow fever, hepatitis, influenza and malaria. CFS was first formally defined in 1988 following studies by the Centers for Disease Control (CDC) in Incline Village, Nevada. However, similar illnesses have been described for many years and known by many names.

Current interest in CFS began in the early 1980s when several groups around the U.S. identified patients with chronic fatiguing illnesses thought to be prolonged infectious mononucleosis based on the clinical presentation and laboratory evidence of what was then considered an active Epstein Barr virus (EBV) infection. Subsequent studies of these cases, including the one in Incline Village, Nevada, did not support a role for an active response to EBV. When the illness was first defined in 1988 the name chronic fatigue syndrome was selected because a more specific name implying known pathophysiology would have been misleading and because the most common and prominent symptom was found to be chronic fatigue (Holmes et al.). Various terms are incorrectly used interchangeably with CFS. CFS has an internationally accepted case definition that is used in research and clinical settings. The name chronic fatigue and immune dysfunction syndrome (CFIDS) was introduced soon after CFS was defined; there is no case definition for CFIDS, and the name implies an understanding about the pathophysiology of CFS that is not fully supported in the medical literature. The name myalgic encephalomyelitis (ME) was coined in the 1950s to clarify well-documented outbreaks of disease; however, ME is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS.

Epidemiology

Prevalence

At least 1 million Americans have CFS. This illness strikes more Americans than multiple sclerosis, lupus, lung cancer or ovarian cancer. It is estimated that 1%–2% of the general population suffers symptoms of CFS and that CFS can be confirmed in between 0.24% and 0.42% of adults. More importantly, there is a general consensus that only 10%–16% of individuals with CFS have been diagnosed by or treated for CFS by a medical professional. The low rate of diagnosis highlights the need for increased awareness of CFS by health care professionals throughout the health care system.

Demographics

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.

Etiology

Many hypotheses concerning the causes and pathophysiology have been raised, but no conclusive evidence in support of any single cause of CFS has been found. The multisystem nature of the illness along with the inherent interrelationship and interdependence of body systems further complicates the search for answers. It is unclear whether CFS has a single cause or represents a common pathophysiologic process following multiple precipitating factors; therefore, the current theories on CFS listed below should not be viewed as mutually exclusive. Each of these theories represents an active area of research and include:

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Infectious Agents

Due in part to its similarity to acute or chronic infections, CFS was initially thought to be caused by a virus infection (i.e., Epstein-Barr (EBV) mononucleosis). It now seems clear that CFS is not caused exclusively by any single recognized infectious disease agent. CDC's four-city surveillance study found no association between CFS and infection by a wide variety of human pathogens, including EBV, human retroviruses, human herpesvirus 6, enteroviruses, rubella, *Candida albicans*, and more recently bornaviruses and *Mycoplasma*. Taken together, these studies suggest that among identified human pathogens, there appears to be no causal relationship for CFS as a whole. However, the possibility remains that CFS may have multiple causes leading to a common endpoint, in which case some viruses or other infectious agents might have a contributory role for a subset of CFS cases. Recently published research suggests that infection with Epstein-Barr virus, Ross River virus and *Coxiella burnetti* will lead to a post-infective condition that meets the criteria for CFS in approximately 12% of cases. The severity of the acute illness was the only factor found to predict which individuals would have persistent symptoms characteristic of CFS at the six-month and one-year period following infection.

Immune System Defects

It has been proposed that CFS may be caused by an immunologic dysfunction, for example inappropriate production of cytokines, such as interleukin-1, or altered capacity of certain immune functions. One thing is certain at this juncture: there are no immune disorders in CFS patients on the scale traditionally associated with disease. Some investigators have observed anti-self antibodies and immune complexes in many CFS patients, both of which are hallmarks of autoimmune disease. However, no associated tissue damage typical of autoimmune disease has been described in patients with CFS. The opportunistic infections or increased risk for cancer observed in persons with immunodeficiency diseases or in immunosuppressed individuals is also not observed in CFS. Several investigators have reported lower numbers of natural killer cells or decreased natural killer cell activity among CFS patients compared with healthy controls, but others have found no differences between patients and controls.

T-cell activation markers have also been reported to have differential expression in groups of CFS patients compared with controls, but again, not all investigators have consistently observed these differences. One intriguing hypothesis is that various triggering events, such as stress or a viral infection, may lead to the chronic expression of cytokines and then to CFS. Administration of some cytokines in therapeutic doses is known to cause fatigue, but no characteristic pattern of chronic cytokine secretion has ever been identified in CFS patients. In addition, some investigators have noted clinical improvement in patients with continued high levels of circulating cytokines; if a causal relationship exists

between cytokines and CFS, it is likely to be complex. Finally, several studies have shown that CFS patients are more likely to have a history of allergies than are healthy controls. Allergy could be one predisposing factor for CFS, but it cannot be the only one, since not all CFS patients have it.

Neuroendocrine Dysfunction

Multiple laboratory studies have suggested that the central nervous system may have an important role in CFS. Physical or emotional stress, which is commonly reported as a pre-onset condition in CFS patients, activates the hypothalamic-pituitary-adrenal axis, or HPA axis, leading to increased release of cortisol and other hormones. Cortisol and corticotrophin-releasing hormone (CRH), which are also produced during the activation of the HPA axis, influence the immune system and many other body systems. They may also affect several aspects of behavior.

Recent studies revealed that CFS patients often produce lower levels of cortisol than do healthy controls. Similar hormonal abnormalities have been observed by others in CFS patients and in persons with related disorders like fibromyalgia. Cortisol suppresses inflammation and cellular immune activation, and reduced levels might relax constraints on inflammatory processes and immune cell activation. As with the immunologic data, the altered cortisol levels noted in CFS cases fall within the accepted range of normal, and only the average between cases and controls allows the distinction to be made. Therefore, cortisol levels cannot be used as a diagnostic marker for an individual with CFS. A placebo-controlled trial, in which 70 CFS patients were randomized to receive either just enough hydrocortisone each day to restore their cortisol levels to normal or placebo pills for 12 weeks, concluded that low levels of cortisol itself are not directly responsible for symptoms of CFS, and that hormonal replacement is not an effective treatment. However, additional research into other aspects of neuroendocrine correlates of CFS is necessary to fully define this important, and largely unexplored, field.

Autonomic Nervous System Dysfunction

Rowe and coworkers conducted studies to determine whether disturbances in the autonomic regulation of blood pressure and pulse (neurally mediated hypotension, or NMH) were common in CFS patients. The investigators were alerted to this possibility when they noticed an overlap between their patients with CFS and those who had NMH. NMH can be induced by using tilt table testing, which involves laying the patient horizontally on a table and then tilting the table upright to 70 degrees for 45 minutes while monitoring blood pressure and heart rate. Persons with NMH will develop lowered blood pressure under these conditions, as well as other characteristic symptoms, such as lightheadedness, visual dimming, or a slow response to verbal stimuli. Many CFS patients experience lightheadedness or worsened fatigue when they stand for

prolonged periods or when in warm places, such as in a hot shower. These conditions are also known to trigger NMH. One study observed that 96% of adults with a clinical diagnosis of CFS developed hypotension during tilt table testing, compared with 29% of healthy controls. Tilt table testing also provoked characteristic CFS symptoms in the patients.

A study (not placebo-controlled) was conducted to determine whether medications effective for the treatment of NMH would benefit CFS patients. A subset of CFS patients reported a striking improvement in symptoms, but not all patients improved. A placebo-controlled trial of NMH medications for CFS patients is now in progress.

Nutritional Deficiency

There is no published scientific evidence that CFS is caused by a nutritional deficiency. Many patients do report intolerances for certain substances that may be found in foods or over-the-counter medications, such as alcohol or the artificial sweetener aspartame. While evidence is currently lacking for nutritional defects in CFS patients, it should also be added that a balanced diet can be conducive to better health in general and would be expected to have beneficial effects in any chronic illness.

Gene Expression

The activation of different genes in CFS is being explored by CDC and other research groups. A preliminary study of gene expression profiles of peripheral blood mononuclear cells of subjects with CFS and healthy controls found eight genes were differentially expressed. Several of the differentially expressed genes are associated with immunologic functions. Another preliminary analysis of microarray data revealed differential expression of 35 genes. Real time PCR confirmed differential expression in the same direction as array results for 16 of these genes with a profile suggesting T cell activation and perturbation of neuronal and mitochondrial function. Further studies of larger patient and control cohorts are ongoing.

Sleep Disorders

The majority of CFS patients report disordered sleep. The results of sleep deprivation on multiple body systems is well-documented and can contribute to fatigue, cognitive dysfunction, pain, alterations in mood and psychological functioning and possibly immune and neuroendocrine disturbances. Further studies on the prevalence and effects of sleep disorders in CFS are needed.

Other Possible Causes

Affective disorders, stress, deconditioning, oxidative stress or defective oxidative metabolism, [cellular] mitochondrial pathology, cardiovascular anomalies and other psychological and physical factors have been explored as possible causes of CFS, but evidence is inconsistent or preliminary. A causative role for these other factors in production of the illness is still undocumented, although they may lead to further complications or serve to prolong illness.

The general consensus of most CFS researchers is that many factors produce the syndrome. It may be that a genetically or situationally predisposed host, when confronted by stress or other insults, comes in contact with a “triggering event” that upsets the body’s normal functions (including the immune and endocrine systems). After this “hit and run” event, flu-like symptoms, pain and cognitive problems result from persistently altered pathways to the central nervous system. Understanding the pathogenesis of CFS—its effect on the body and the brain—is a primary goal of ongoing biomedical research.

CFS Case Definition

CFS is a clinically diagnosed condition with a well-documented history; however, there is not a definitive cause or cure for the condition. This has caused considerable debate among patients, physicians, and researchers about how to accurately characterize and reflect its multifaceted components. In addition, the symptoms of CFS are variable and differ in severity, making a definitive description difficult. In order to navigate its complexities, it is helpful to consider the many variants that make up CFS. While the Fukuda definition is the accepted standard for research studies, many suggest that modifications as suggested by the International Study Group should be adopted. A chronological listing of diagnostic criteria from the United States and countries around the world follows.

Epstein-Barr Virus Syndrome (EBV)

In the early 1980s, patients with symptoms including fatigue, muscle pain, and depression were often diagnosed with chronic Epstein-Barr virus syndrome or chronic mononucleosis syndrome. These patients had symptoms that suggested infection, such as low-grade fever, recurrent sore throat, and tender lymph nodes. Epstein-Barr virus (EBV), which causes acute mononucleosis, was considered a likely source. But researchers could not isolate EBV as the cause of the syndrome and, as yet, have not definitively identified any other infectious agents.

CDC Definition (Holmes, et al., 1988)

In 1988, in an effort to standardize research definitions, a group of experts led by the Centers for Disease Control and Prevention (CDC) proposed a new name for

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Epstein-Barr virus syndrome that more accurately described it: chronic fatigue syndrome.

The first formal case definition included two major criteria along with the following minor criteria: 6 or more of the symptom criteria listed below and 2 or more of the physical criteria; or 8 or more symptom criteria.

Major criteria:

1. New onset of persistent or relapsing, debilitating fatigue or easy fatigability in a person who has no previous history of similar symptoms, that does not resolve with bed rest, and that is severe enough to reduce or impair average daily activity below 50 percent of the patient's premorbid activity level for a period of at least 6 months
2. Exclusion of other clinical conditions that may produce similar symptoms (e.g., malignancy, autoimmune disease, chronic psychiatric disease, and chronic inflammatory disease, among others)

Minor criteria:

Symptom criteria

1. Mild fever
2. Sore throat
3. Painful lymph nodes in the anterior or posterior cervical or axillary distribution
4. Unexplained generalized muscle weakness
5. Muscle discomfort or myalgia
6. Prolonged (≥ 24 hours) generalized fatigue after exercise
7. Generalized headaches
8. Migratory arthralgia without joint swelling or redness
9. Neuropsychologic complaints
10. Sleep disturbance

Physical criteria

1. Low-grade fever
2. Nonexudative pharyngitis

Australian Definition (Lloyd et al., 1990)

At the same time as CDC's effort, researchers in Australia developed their own case definition of CFS. The Australian definition captured CDC's major criteria, and added the symptom of "neuropsychiatric dysfunction," which included impairment of concentration and short-term memory.

The Australian criteria consisted of the following symptoms:

1. Chronic persisting or relapsing fatigue of a generalized nature, exacerbated by minor exercise, causing significant disruption of usual daily activities, and present for more than 6 months
2. Neuropsychiatric dysfunction including impairment of concentration evidenced by difficulty in completing mental tasks which were easily

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accomplished before the onset of the syndrome; new onset of short term memory impairment

3. No alternative diagnosis reached by history, physical examination, or investigations over a 6-month period

British Definition (Sharpe et al., 1991)

A 1990 consensus meeting of researchers in Great Britain found neither of these definitions satisfactory in practice. The resulting guidelines included a glossary describing in detail the principal symptoms of fatigue, disability, mood disturbance, myalgia (muscle pain), and sleep disturbance. The "Oxford criteria," as they came to be known, also defined post-infectious fatigue syndrome (PIFS), a subtype of CFS that either follows an infection or is associated with a current infection.

The "Oxford criteria" defined two broad syndromes: chronic fatigue syndrome and post-infectious fatigue syndrome (PIFS). CFS was defined by the following characteristics:

1. Fatigue is the principal symptom.
2. It is a syndrome of definite onset that is not lifelong.
3. Fatigue is severe, disabling, and affects physical and mental functioning.
4. Fatigue has been present for a minimum of 6 months, during which it was present for more than 50 percent of the time.
5. Other symptoms may be present, particularly myalgia, mood, and sleep disturbance.
6. Exclusion criteria included patients with established medical conditions known to produce chronic fatigue and those with certain psychiatric disorders (substance abuse, eating disorders, organic brain disease).

PIFS was considered a subtype of CFS that either follows an infection or is associated with a current infection. PIFS fulfills all the criteria for CFS as well as the following:

1. Definite evidence of infection at onset or presentation
2. Present for a minimum of 6 months after onset of infection
3. Infection corroborated by laboratory evidence

International Definition (Fukuda et al., 1994)

In response to criticisms of the original CDC definition of CFS as too ambiguous and over-exclusive, and to facilitate a more systematic collection of data internationally, the International Chronic Fatigue Syndrome Study Group, headed by CDC and including representatives from Australia and Great Britain, proposed a revised CFS case definition in 1994.

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This revision of the 1988 CDC case definition remains the currently accepted research definition, also known as the Fukuda definition, and was based on the presence of the following:

1. Clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities
2. The concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue:
 1. Self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities
 2. Tender cervical or axillary lymph nodes
 3. Muscle pain, multijoint pain without joint swelling or redness
 4. Headaches of a new type, pattern, or severity
 5. Unrefreshing sleep
 6. Postexertional malaise lasting more than 24 hours

Canadian Definition (Carruthers et al., 2003)

An expert consensus panel convened in Canada in 2001 and developed a case definition of ME/CFS designed for clinical diagnoses, rather than for research purposes as was the 1994 definition of CFS. The panel outlined criteria for the symptom categories of fatigue; post-exertional malaise or fatigue; sleep dysfunction; pain; and body system manifestations including neurological/cognitive (e.g., difficulties with memory or concentration), autonomic (e.g., vertigo), neuroendocrine (e.g., heat or cold intolerance), and immune (e.g., sore throat).

1. *Fatigue*: Significant degree of new-onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.
2. *Post-exertional malaise and/or fatigue*: Loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue, malaise and/or pain, and a tendency for other symptoms to worsen. A pathologically slow recovery period (more than 24 hours).
3. *Sleep dysfunction*: Unrefreshing sleep or poor sleep quality; rhythm disturbance such as reversed or chaotic diurnal sleep rhythms.
4. *Pain*: Significant degree of myalgia experienced in muscles and/or joints; often widespread and migratory in nature. Often, significant headaches of new type, pattern, or severity.
5. *Neurological/cognitive manifestations*: Two or more of the following: confusion; impairment of concentration and short-term memory

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consolidation; disorientation; difficulty with information processing, categorizing, and word retrieval; and perceptual/sensory disturbances. Possible cognitive or sensory overload (e.g., photophobia, hypersensitivity to noise) and/or emotional overload leading to relapses.

6. At least one symptom from two of the following categories:
 1. *Autonomic manifestations*: Orthostatic intolerance, light-headedness, extreme pallor, nausea and irritable bowel syndrome, urinary frequency and bladder dysfunction, palpitations with or without cardiac arrhythmia, exertional dyspnea.
 2. *Neuroendocrine manifestations*: Loss of thermostatic stability, heat/cold intolerance, marked weight change, loss of adaptability and worsening of symptoms with stress.
 3. *Immune manifestations*: Tender lymph nodes; recurrent sore throat; flu-like symptoms; general malaise; new sensitivities to food, medications, and/or chemicals.
7. Illness persisting for at least 6 months. Usually acute onset, but may be gradual.

International Definition - revisited (Reeves et al., 2003)

In 2003, the international study group revisited the 1994 case definition of CFS to identify and address ambiguities, with the goal of facilitating future research. The original definition offered examples of conditions that would preclude a diagnosis of CFS. The study group elaborated on these exclusionary criteria, and recommended the use of several specific standardized instruments in assessing fatigue and accompanying symptoms.

1. Permanent medical exclusions:
 1. Organ failure (e.g., emphysema, cirrhosis, cardiac failure, chronic renal failure)
 2. Chronic infections (e.g., AIDS, hepatitis B or C)
 3. Rheumatic and chronic inflammatory diseases (e.g., systemic lupus erythematosus, Sjogren's syndrome, rheumatoid arthritis, inflammatory bowel disease, chronic pancreatitis)
 4. Major neurologic diseases (e.g., multiple sclerosis, neuromuscular diseases, epilepsy or other diseases requiring ongoing medication that could cause fatigue, stroke, head injury with residual neurologic deficits)
 5. Diseases requiring systemic treatment (e.g., organ or bone marrow transplantation; systemic chemotherapy; radiation of brain, thorax, abdomen, or pelvis)
 6. Major endocrine diseases (e.g., hypopituitarism, adrenal insufficiency)
 7. Primary sleep disorders (e.g., sleep apnea, narcolepsy)
2. Temporary medical exclusions:

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1. Conditions discovered at onset or initial evaluation (e.g., effects of medications, sleep deprivation, untreated hypothyroidism, untreated or unstable diabetes mellitus, active infection)
 2. Conditions that resolved (e.g., pregnancy until 3 months post-partum, breastfeeding, major surgery until 6 months post-operation, minor surgery until 3 months post-operation, major infections such as sepsis or pneumonia until 3 months post-resolution)
 3. Major conditions whose resolution may be unclear for at least 5 years (e.g., myocardial infarction, heart failure)
 4. Morbid obesity (body mass index > 40)
3. Permanent psychiatric exclusions:
Lifetime diagnoses of bipolar affective disorders, schizophrenia of any subtype, delusional disorders of any subtype, dementias of any subtype, organic brain disorders, and alcohol or substance abuse within 2 years before onset of the fatiguing illness

Diagnosis

Diagnostic Overview

By definition, all people suffering from CFS experience severe all-encompassing mental and physical fatigue that is not relieved by rest. The fatigue is accompanied by characteristic symptoms and these may be more bothersome to the patient than the fatigue. For example, almost all people with CFS report cognitive problems, such as difficulty with concentration and memory, word-finding and inability to do even simple math. In many patients, mental fatigue may be more bothersome than physical fatigue. Most patients also describe sleep problems (getting to sleep or staying asleep), and report that no amount of sleep leaves them refreshed — they awake feeling as if they have never been to sleep at all. Finally, pain (muscle, joint or headache) may be the primary complaint.

CFS symptoms vary from person to person in type, number and severity and it appears that no two people present with exactly the same symptom set. All of these facts add to the complexity of making a CFS diagnosis.

Recognition and diagnosis of CFS can be challenging for health care professionals. Fatigue is a common symptom of many illnesses; between 10 and 25% of all patients who visit general practitioners complain of prolonged fatigue. Symptoms that comprise CFS are common in other conditions. Diagnosis of CFS can be made only after a thorough physical and mental status exam and appropriate laboratory testing to rule out diseases for which specific treatment exists and that may be responsible for the patient's symptoms.

Healthcare professionals from many disciplines may encounter CFS patients at any point in the evaluation and management process. Primary care professionals are often the first to be consulted by people seeking a diagnosis and relief from their multiple, ongoing symptoms. Rehabilitation and behavioral professionals may see CFS patients seeking evaluation and treatment of pain disorders, poor physical function and mental health concerns. These patients may also seek care to help them cope with interpersonal and lifestyle changes, decreased stamina or employment problems stemming from poor health (whether diagnosed or not). In addition, CFS patients may have mood symptoms, such as anxiety and depression, for which they seek evaluation and treatment from healthcare professionals.

Differential Diagnosis and Exclusionary Conditions

As mentioned previously, patients with chronically fatiguing illness should be carefully evaluated medically and psychiatrically both early in the diagnostic process and throughout their care. Many diseases present similarly to CFS, and these must receive appropriate evaluation and treatment before considering CFS as a diagnosis. Examples include: 1) conditions discovered during evaluation (e.g., effects of medications or dietary supplements, sleep disorders, untreated hypothyroidism, diabetes, infection, hypertension, menopause, obesity); 2) conditions that resolve on their own (e.g., pregnancy, recent surgery); and 3) chronic diseases whose resolution may be unclear for some time (e.g., myocardial infarction, heart failure).

Other medical diseases exclude the diagnosis of CFS in research studies and include: 1) organ failure (e.g., emphysema, cirrhosis, renal disease, cardiac diseases); 2) chronic infections (e.g., AIDS, hepatitis B or C); 3) rheumatic and chronic inflammatory diseases (e.g., systemic lupus erythematosus, rheumatoid arthritis, inflammatory bowel disease, chronic pancreatitis); 4) major neurological diseases (e.g., multiple sclerosis, neuromuscular diseases, epilepsy, stroke, head injury); 5) major endocrine diseases (e.g., adrenal insufficiency, hypopituitarism); 6) cancer and 7) primary sleep disorders (e.g., sleep apnea, narcolepsy).

Note that these conditions are considered exclusionary only in the research setting to ensure that patients in research studies have no known underlying diseases. In clinical practice, patients with the conditions mentioned above (and many others) may describe the same constellation of symptoms. The clinical professional must exercise care and judgment to assess the contribution of known diseases to the symptoms reported by the patient and could use the above exclusionary conditions as a guide. During a careful medical evaluation, CFS can be considered as a 'working' or tentative diagnosis so that appropriate treatment for symptoms may begin during the diagnostic process.

Health care professionals caring for patients with CFS should also consider the possibility of an underlying or comorbid psychiatric condition. Several psychiatric disorders exclude the diagnosis of CFS and include lifetime occurrence of bipolar affective disorders, schizophrenia of any subtype, delusional disorders of any subtype, dementias of any subtype and organic brain disorders. Melancholic depression, alcohol or substance abuse, anorexia nervosa or bulimia are not necessarily exclusionary conditions; a thorough clinical evaluation must be completed to ensure that the illness has resolved before considering CFS.

Comorbid Conditions

CFS patients may also present with other medically unexplained conditions, such as fibromyalgia, Gulf War illness, anxiety disorders, somatoform disorders, irritable bowel syndrome, orthostatic intolerance, temporomandibular joint disorder and multiple chemical sensitivity. Some authors have proposed that these illnesses are part of the same continuum as CFS. Appropriate therapy and rehabilitation of people with CFS and these unexplained conditions should address the cumulative symptom complex and not center on a specific diagnosis.

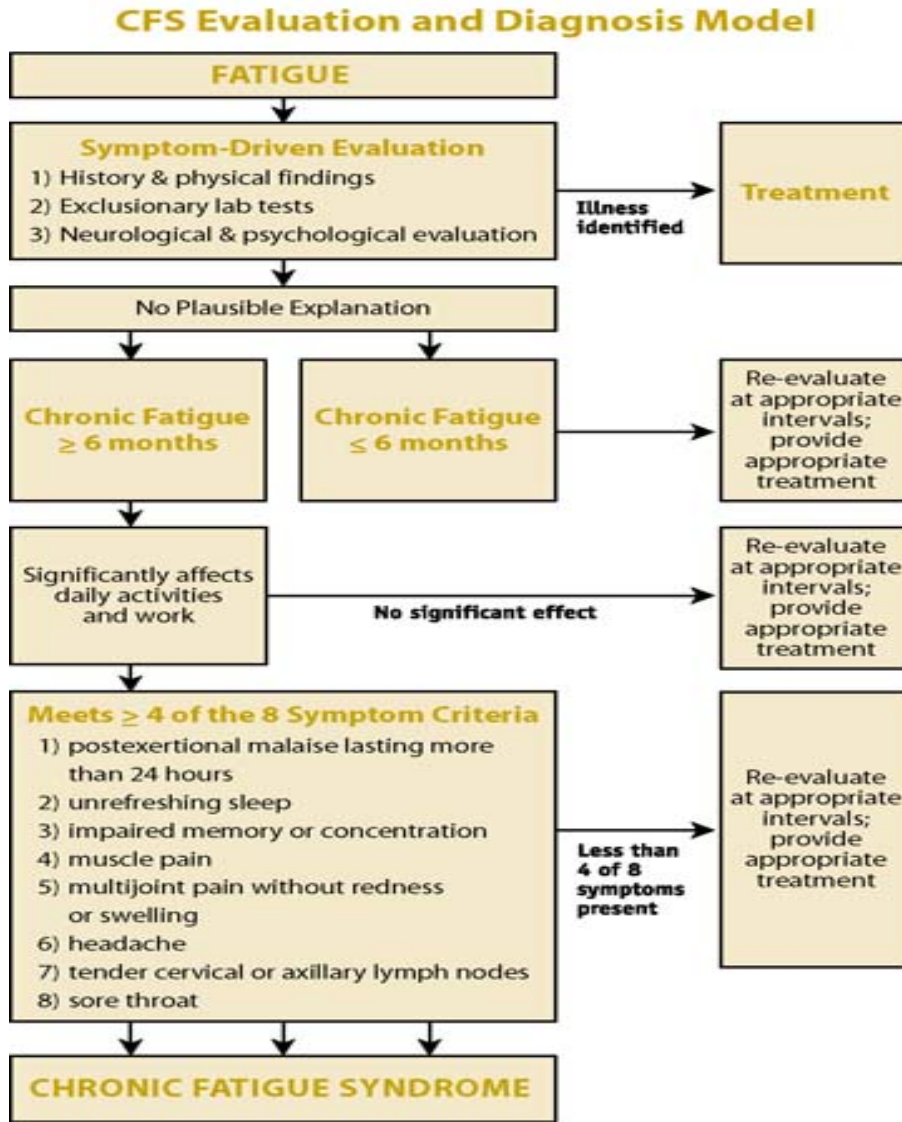
Patients with CFS may also have other diseases, including hypothyroidism, diabetes, asthma, allergies, heart disease and Lyme disease. These comorbid conditions must be considered when the health care professional is developing a therapeutic plan, since effective treatment must address both CFS and the accompanying illness. Health care professionals responsible for treatment of patients with CFS should also keep in mind that changes in symptoms may represent exacerbation of the comorbid condition rather than CFS.

It is critical that health care professionals are aware that people with CFS can develop other serious illnesses for which there is specific treatment. The symptoms of CFS wax and wane in occurrence and severity; however, changes in symptoms or impairment should not be automatically attributed to the CFS diagnosis.

Evaluation and Diagnosis Model

Given the complexity of CFS, how can health care professionals diagnose the presence of chronic fatigue syndrome with a greater degree of confidence? Drs. Nancy Klimas and Charles Lapp created a decision-making model from the case definition to guide clinical assessment of patients with CFS-like symptoms. This model provides a step-wise approach to making a sound clinical diagnosis.

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The physical exam focuses on ruling out alternative diagnoses. Clinical evaluation of people with a fatiguing illness requires:

1. a detailed patient history, including review of medications that could cause fatigue;
2. a thorough physical examination;
3. a mental status screening; and
4. a minimum battery of laboratory screening tests.

Recommended lab tests include:

- Urinalysis
- Complete blood count (CBC) with leukocyte differential
- Erythrocyte sedimentation rate (ESR)

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

Routinely doing other laboratory tests for all patients with chronically fatiguing illnesses has limited value. For example, it is inappropriate to test initially for antibodies to EBV in all people with CFS symptoms, even though EBV can be associated with a prolonged infection that has all the features of CFS. Diagnosis requires a complete clinical evaluation and cannot be accomplished by merely testing for antibodies. Since 95% of adults have been infected with EBV, most adults will show antibodies to EBV from infection incurred years earlier. High or elevated antibody levels may be present for years and are not diagnostic of recent infection. Studies have shown that EBV antibodies can be present in 20% of healthy individuals for years.

Further tests may be indicated to confirm or exclude other diagnoses, which better explain the persistent fatigue state (e.g., polysomnography for a patient with suspected sleep apnea or a multiple sleep latency test for narcolepsy). A mental state examination of individuals with fatigue should focus on observed behavioral features in addition to symptoms reported by the patient. These include psychomotor slowing, cognitive impairment, odd interpersonal behavior and angry/hostile responses. In addition, it is important to evaluate the individual's risk of suicide.

Although CFS requires fatigue of at least six months duration, initial evaluation of patients with fatigue should not focus on fatigue as a distinct entity. Rather, the entire presenting symptom complex must be evaluated. If the patient has had symptoms of chronic fatigue for less than six months, then he/she needs to be re-evaluated depending on the results of the physical evaluation. Also, it is important to remember that six months is not a magic number. One should not wait until fatigue has been present for six months or longer to consider the patient's complaints. Appropriate evaluation and therapy need to be initiated early.

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If the fatigue is chronic/relapsing for six or more consecutive months and is unrelieved by bed rest, then determine if the fatigue has significantly affected the patient's lifestyle, ability to work or attend school.

If no other plausible explanations are found for the fatiguing illness, then assess the patient to see if he or she meets four or more of the eight CFS symptom criteria. However, the primary health care professional should exercise judgment here, based on the course of illness, other symptomology and the patient's medical history. Fewer than four of the eight symptom criteria may be diagnostic for a non-syndromic chronic fatigue.

If the patient has had more than six months of fatigue and indicates that it has not had a major effect on his/her lifestyle or work then the patient should be diagnosed with non-syndromic chronic fatigue. Conservative treatment with periodic follow-up is appropriate.

CFS is excluded if another plausible explanation is found. Confounding conditions need to be treated and the patient needs to be re-evaluated regularly.

If all diagnostic criteria are met, and other plausible conditions have been ruled out, the diagnosis of CFS can be made.

Conditions that Exclude a Diagnosis of CFS

1. Any active medical condition that may explain the presence of chronic fatigue, such as untreated hypothyroidism, sleep apnea and narcolepsy, and iatrogenic conditions such as side effects of medication.
2. Some diagnosable illnesses may relapse or may not have completely resolved during treatment. If the persistence of such a condition could explain the presence of chronic fatigue, and if it cannot be clearly established that the original condition has completely resolved with treatment, then such patients should not be classified as having CFS. Examples of illnesses that can present such a picture include some types of malignancies and chronic cases of hepatitis B or C virus infection.
3. Any past or current diagnosis of a major depressive disorder with psychotic or melancholic features;
 - bipolar affective disorders
 - schizophrenia of any subtype
 - delusional disorders of any subtype
 - dementias of any subtype
 - anorexia nervosa
 - or bulimia nervosa
4. Alcohol or other substance abuse, occurring within 2 years of the onset of chronic fatigue and any time afterwards.
5. Severe obesity as defined by a body mass index equal to or greater than 45. [Note: body mass index values vary considerably among different age

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groups and populations. No "normal" or "average" range of values can be suggested in a fashion that is meaningful. The range of 45 or greater was selected because it clearly falls within the range of severe obesity.]

Any unexplained abnormality detected on examination or other testing that strongly suggests an exclusionary condition must be resolved before attempting further classification.

Conditions that do not Exclude a Diagnosis of CFS

1. Any condition defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, including fibromyalgia, anxiety disorders, somatoform disorders, nonpsychotic or melancholic depression, neurasthenia, and multiple chemical sensitivity disorder.
2. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented. Such conditions include hypothyroidism for which the adequacy of replacement hormone has been verified by normal thyroid-stimulating hormone levels, or asthma in which the adequacy of treatment has been determined by pulmonary function and other testing.
3. Any condition, such as Lyme disease or syphilis, that was treated with definitive therapy before development of chronic symptoms.
4. Any isolated and unexplained physical examination finding, or laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition. Such conditions include an elevated antinuclear antibody titer that is inadequate, without additional laboratory or clinical evidence, to strongly support a diagnosis of a discrete connective tissue disorder

Clinical Course

The severity of CFS varies from patient to patient, with some people able to maintain fairly active lives. By definition, however, CFS significantly limits work, school and family activities.

While symptoms vary from person to person in number, type and severity, all CFS patients are functionally impaired to some degree. 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 often follows a cyclical course, alternating between periods of illness and relative well-being. Some patients experience partial or complete remission of symptoms during the course of the illness, but symptoms often reoccur. This pattern of remission and relapse makes CFS especially hard for patients and

their health care professionals to manage. Patients who are in remission may be tempted to overdo activities when they're feeling better, which can exacerbate symptoms and fatigue and cause a relapse. In fact, postexertional malaise is a hallmark of the illness.

The percentage of CFS patients who recover is unknown, but there is some evidence to indicate that the sooner symptom management begins, the better the chance of a positive therapeutic outcome. This means early detection and treatment are of utmost importance. CDC research indicates that delays in diagnosis and treatment may complicate and prolong the clinical course of the illness.

Symptomology

As the name chronic fatigue syndrome suggests, this illness is accompanied by fatigue. However, it's not the kind of fatigue patients experience after a particularly busy day or week, after a sleepless night or after a stressful event. It's a severe, incapacitating fatigue that isn't improved by bed rest and that may be exacerbated by physical or mental activity. It's an all-encompassing fatigue that results in a dramatic decline in both activity level and stamina.

People with CFS function at a significantly lower level of activity than they were capable of prior to becoming ill. The illness results in a substantial reduction in occupational, personal, social or educational activities.

Subjective Complaints

Primary subjective complaints include:

- cognitive dysfunction, including impaired memory or concentration
- postexertional malaise lasting more than 24 hours (exhaustion and increased symptoms) following physical or mental exercise
- unrefreshing sleep
- joint pain (without redness or swelling)
- persistent muscle pain
- headaches of a new type or severity
- tender cervical or axillary lymph nodes
- sore throat

In addition to the primary symptoms of CFS, a number of other symptoms have been reported by some CFS patients. The frequency of occurrence of these symptoms varies among patients.

These symptoms include:

- irritable bowel, abdominal pain, nausea, diarrhea or bloating
- chills and night sweats
- brain fog

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- chest pain
- shortness of breath
- chronic cough
- visual disturbances (blurring, sensitivity to light, eye pain or dry eyes)
- allergies or sensitivities to foods, alcohol, odors, chemicals, medications or noise
- difficulty maintaining upright position (orthostatic instability, irregular heartbeat, dizziness, balance problems or fainting)
- psychological problems (depression, irritability, mood swings, anxiety, panic attacks)
- jaw pain
- weight loss or gain

Sleep Disturbances

Unrefreshing sleep is a major CFS symptom. Sleep abnormalities are an important differential diagnosis and comorbidity for CFS. In one study, CFS subjects are more likely to have non-restorative sleep and 16 times more likely to have restlessness, compared to non-fatigued subjects. Such problems require evaluation by a sleep specialist. Sleep disturbances may cause or exacerbate other symptoms, and may also be a side effect of certain medications, including those used to treat mood disorders.

Sleep deprivation or disruption produces many features of CFS, including fatigue, impaired cognition and even joint pain and stiffness. Primary sleep disorders such as sleep apnea and narcolepsy exclude the diagnosis of CFS and most people with such disorders respond to therapy. Thus, it is imperative that a careful sleep history be obtained. The Pittsburgh Sleep Questionnaire, a validated 19 question tool, or a brief sleep survey, adapted for clinical use can be helpful in assessing sleep problems and tracking effectiveness of sleep management interventions.

Sleep complaints common among people with CFS include difficulty falling asleep, hypersomnia, frequent awakening, intense and vivid dreaming, restless legs, periodic leg movements and nocturnal myoclonus. Most patients experience non-restorative sleep, a feeling of profound fatigue, achiness and mental “fogginess” that lasts 1–2 hours after rising.

Health care professionals can help people with CFS adopt better sleep habits, in accordance with standard sleep hygiene techniques. These techniques are often incorporated in a comprehensive CBT program, but can also be useful outside the scope of such programs. Specifically, patients are advised to incorporate an extended wind-down period, use the bed only for sleep and sex, schedule regular sleep and wake times and complete even light exercise at least 4 hours before going to bed.

Unmediated sleep is best, but when sleep hygiene measures are not successful, the use of pharmaceuticals may be indicated. Initial medications to consider are simple antihistamines (such as diphenhydramine) or over-the-counter sleep products. As noted earlier, because of possible medication sensitivity, it is best to start with low doses and increase to tolerance. If this is not beneficial, then start with a prescription sleep medicine in the smallest possible dose and for a brief period. Hypnotics are to be avoided. Patients need to be informed that sleep and sedative medications may produce their own problems and undesirable side effects. Judicious use of these drugs is important. Non-restorative sleep can be present even though medications may allow requisite hours of sleep. A sleep specialist should evaluate patients whose sleep remains nonrestorative following the above interventions.

Depression

Depression commonly accompanies CFS and should be treated when present. It is incorrect to assume that all people with CFS have depression or that CFS is a form of depression.

Health care professionals are advised to use caution in prescribing antidepressants. Antidepressant drugs of various classes have other effects that may act on other CFS symptoms and/or cause side effects. There are brief psychiatric screening tools available that can be administered and scored in the primary care setting, such as the Beck Depression Inventory and the Patient Health Questionnaire nine-item depression scale, the PHQ-9. Results of these screening tools that point to a possible underlying depression or other psychological disorder necessitate a referral to a mental health professional.

Finally, as noted previously, many people with chronic illnesses, including those with CFS, may suffer from depression. Feelings of worthlessness, inappropriate guilt, recurrent thoughts of death, recurrent suicidal ideation, suicide attempts or a specific plan for committing suicide define major depressive disorders. Mental health professionals in particular should be aware of and address this as necessary. All health care professionals who are responsible for treatment and rehabilitation of CFS patients should also be aware that inappropriately counseled CFS patients can become suicidal.

Pain

CFS pain may be in muscles (sometimes described as “deep pain”) or joints (arthralgias). Patients may also complain of headaches (typically pressure-like) and allodynia, which is generalized hyperalgesia or soreness of the skin to touch.

Therapy may begin pharmacologically with simple analgesics like acetaminophen, aspirin or NSAIDs and should include non-pharmacological modalities, such as graded exercise, paced activity, gentle massage, physical

therapy, transcutaneous electric nerve stimulation (TENS) units, cool or hot packs, meditation, relaxation, deep-breathing and biofeedback.

Counseling for pain management techniques is advisable for people with severe, unremitting pain. Narcotics should be considered an option only in consultation with a pain management specialist.

Orthostatic Problems

Some patients with CFS may also exhibit symptoms of orthostatic instability, in particular frequent dizziness and light-headedness. Depending on severity and clinical judgment, these patients should be referred for evaluation by a cardiologist or a neurologist. Specific treatment for orthostatic instability should only be initiated following confirmed diagnosis and by clinicians experienced in evaluating therapeutic results and managing possible complications

Other Issues Associated with CFS

For many people with CFS, there are a number of other issues that must be addressed and resolved before improvement in CFS can be expected.

Stress, Anxiety and Depression

Many people with CFS experience symptoms of stress, anxiety and depression. Stress and anxiety may be reduced through relaxation training and resolution of their origins, and in some cases, combining medication and talk therapy may be required.

Cognitive Dysfunction

Memory and concentration complaints are two of the more distressing symptoms reported by 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. Behavioral health professionals may help the patient problem-solve and develop specific techniques for conducting activities of daily living that have become difficult. Referral to a neuropsychologist, neurologist or psychiatrist for evaluation and testing may be necessary in severe cases to determine whether other underlying conditions may be involved. It should be noted that training to improve cognition is a highly specialized therapy and requires input of trained behavioral health clinicians.

Family Issues

CFS impacts the entire family structure. In many cases the health care professionals will want to involve other family members to educate them and to

resolve issues resulting from or related to CFS. This option is particularly true in the case of an adolescent with CFS.

Empathy

People with CFS often feel misunderstood and isolated. They need reassurance that their health care professionals do not attribute all of their symptoms to psychological problems, accept their CFS diagnosis and the reality of their suffering and provide an environment where they may safely discuss issues regarding the impact of their illness.

Therapeutic Strategies

Once a medical provider has diagnosed CFS, the allied health professional can develop a therapeutic care plan. This plan should begin with evaluation of the impact of the illness on the individual's quality of life and the identification of those areas of greatest need or concern to the patient. This evaluation should document existing impairment and disability to guide development of an individualized management plan and to provide a baseline against which to assess the effects of treatment.

The simplest and most effective way to evaluate CFS patients is to ask them to identify their concerns in order of importance and severity and then assess the relative impact of each on quality of life. Practitioners should employ their usual methods of evaluating the most important specific concerns and rely on their experience to develop a therapeutic plan.

Assessment

Standardized and validated instruments are available to assess specific areas of impairment and to evaluate the occurrence and severity of individual symptoms in a quantitative manner (see Appendix A). These instruments may be particularly useful to practitioners and clinics specializing in the care of people with CFS and in documenting disability for third-party providers. CDC recommends the use of the Medical Outcomes Survey Short Form-36 (SF-36) to formally assess impairment and disability. This is a well-validated instrument that measures the effects of the entire illness on physical activity, social activity, usual role activities, bodily pain, general mental health, vitality and health perceptions. Considerable normative data are available for many illnesses, including CFS. The SF-36 is proprietary; however, a clinical version, the Rand-36, is freely available to any practitioner.

Also recommended is the recently validated CDC Symptom Inventory to assess the impact of CFS case-defining and other symptoms. The instrument has been used in studies of CFS, other fatiguing illness and non-fatigued controls identified

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in the general population. Finally, the Multidimensional Fatigue Inventory (MFI) can be used to quantify the level of fatigue and its consequences. All three instruments are self-administered by patients and can be completed in a relatively short time period. Use of this battery of tests follows the recommendations of the CDC's empirical approach to CFS definition.

There are other tools that address specific areas of impairment, for instance, a visual pain rating scale is an efficient method for documenting levels of pain in specific areas. Standard tests of strength and flexibility, such as grip strength (e.g., hand dynamometry), sit-and-reach, muscle flexibility (e.g., goniometry) and consecutive sit-to-stand repetitions in 30 seconds should be done when applicable.

Exercise testing may be indicated to evaluate deconditioning. People with CFS should be advised to avoid other activities on the day testing is scheduled because symptoms will likely be exacerbated.

The following types of questions can be helpful in assessing people with CFS before, during and after activity/exercise sessions that are designed for rehabilitation.

At the initial appointment:

- What is a typical day like for you since becoming ill?
- What activities do you do?
- What are your three greatest problems or concerns?
- What are your goals for therapy?

During the rehabilitation session:

- How hard are you working? (Use the Borg or other perceived exertion scale)
- How are you feeling?

The day after the session:

- Ask patients to call you 24 hours after the appointment to report how they are feeling. This helps the provider assess whether the activity provoked an exacerbation of illness and should be modified.

At the next session:

- How did you feel after the last session?
- If home-based exercise or activity was prescribed, were you able to do it? How did you feel during and afterward?
- What other activities did you do on the day(s) you did rehabilitation? (An activity diary, described below, can be a helpful adjunct to this direct patient report.)

Activity Diary

In an activity diary, people with CFS are asked to briefly chart their daily activities and health status. This can be important in assessing activity and its impact on function, symptoms and health. A diary may reveal patterns of activity that exacerbate symptoms, and this can be changed to promote better function. However, such diaries may reinforce symptom focusing, which may cause some patients to feel worse, and subsequently the diary serves to undermine therapeutic efforts that are designed to change certain behavior patterns. Activity and symptom diaries may be very effective during early phases of the therapy process, but become less effective or more difficult to maintain during later phases of therapy. Therapists should use sound clinical judgment and consider issues of client appropriateness, treatment goals and timing when utilizing activity and symptom diaries.

Many practitioners have developed their own means of assessing symptoms and disability. Practitioners are encouraged to rely on their clinical experience because there are currently no standardized guidelines for monitoring or managing CFS.

Management Goals

The objective of an effective management program for chronic fatigue syndrome is threefold:

1. To help patients develop effective coping strategies for living with a life-altering illness,
2. To relieve symptoms and
3. To teach patients to manage activity levels to avoid postexertional malaise on the one extreme and deconditioning on the other.

While symptom management is critical to CFS care, prescribing treatments to address individual symptoms without simultaneously addressing the emotional and psychosocial issues related to the CFS experience may not be effective. In fact, a patient's unresolved anger, guilt and anxiety may actually exacerbate symptoms, or interfere with pharmacologic therapies.

Health care practitioners should recognize that there appears to be considerable variability in CFS symptom expression, symptom severity and the efficacy of specific treatment protocols. There is no known cure, and a therapy that works for one CFS patient may be of little benefit to another. While this can make managing CFS challenging, there are treatment strategies that can not only help your patients, but contribute to a more rewarding therapist-patient relationship.

Often, people with CFS were highly active, productive individuals before they became ill. Helping patients adjust their expectations to the limitations imposed

by CFS can help reduce negative feelings of stress, anxiety or anger, all of which can exacerbate symptoms. Therapists are encouraged to assist people with CFS to understand that hope for improvement is realistic, but immediate and complete restoration of pre-illness functioning is not the initial emphasis of therapy.

Although no specific intervention has been shown to cure or to lead to resolution of CFS, multidisciplinary approaches leading to adaptation have been shown to reduce symptoms and improve quality of life. Approaching the illness from this perspective may help individuals initially cope better with the frustration of living with CFS and ultimately facilitate effective self-management and symptom improvement.

Ideally, a multidisciplinary team of health care professionals (e.g., physicians, physician assistants, nurse practitioners and other primary care professionals, mental health professionals, rehabilitation professionals) working together to develop an individualized, coordinated care plan would best serve the patient. Realistically, ongoing coordination of care is difficult to achieve, given financial, time and logistical constraints. However, health care professionals who are responsible for overall or component management are encouraged to use recommendations provided by other disciplines and to contact health care professionals who may be receptive to coordinated care.

A complete history and physical will often take more time than the standard office visit. Recognizing time limitations, written assessment tools that measure fatigue intensity, functional disability, sleep problems or mental health concerns can be given to the patient to fill out between visits or upon early arrival to the office.

Exercise

Exercise Overview

Advising patients who have chronic fatigue syndrome to engage in aerobic exercise and “go for the burn” or “release those endorphins” can be detrimental. Most CFS patients cannot tolerate traditional exercise routines aimed at optimizing aerobic capacity. Instead of helping patients, such vigorous exercise can cause postexertional malaise, a hallmark of CFS that is defined as exacerbation of fatigue and other symptoms following physical or mental exertion. Even worse, this kind of exercise can precipitate a full-scale relapse that lasts for days or weeks.

A different way of defining exercise and managing activity is needed for CFS patients and their health care team.

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The objective of exercise and activity management is to find a balance that allows patients to avoid postexertional malaise and prevent deconditioning so they can achieve better function and improved quality of life.

Some people with CFS inappropriately avoid all activity because personal experience has demonstrated a link between exertion and symptom severity. An even greater number of people engage in an endless “push-crash” cycle in which they do too much, crash, rest, start to feel a little better and do too much once again, perpetuating the cycle.

It is important that emphasis be placed on avoiding these two extremes and balancing activity. Appropriate rest is an important element of CFS management, and patients must learn to stop activity before illness and fatigue are worsened. In the early stages of resumed activity, patients should avoid becoming tired with physical activity.

Postexertional Malaise

Postexertional malaise and exercise intolerance are key symptoms of CFS and may help distinguish CFS from many other medical and psychological conditions. Activity that would rejuvenate or cause little trouble for a healthy person can result in a worsening of symptoms that necessitates days of bedrest. In one study, 75% of people with untreated CFS who performed a 5- to 12-minute incremental low-intensity treadmill test took longer than 3 days to recover. Therapists should carefully consider this aspect of CFS when selecting and implementing interventions and should monitor and document patients’ reports of activity and exercise exacerbating symptoms. Having patients briefly track symptoms and function in a diary may more clearly illuminate this association for the patient and the therapist.

Graded Activity

The goals of graded activity are encouraging healthy, balanced activity patterns and promoting feelings of control and self-efficacy, important predictors of outcome in CFS patients. Controlled trials have shown that graded exercise can be effective in decreasing fatigue and improving functioning.

In contrast to exercise or conditioning programs for healthy people, graded activity or exercise in CFS management begins at much lower levels and increases more slowly. The initial goal should be to prevent further deconditioning. The temptation to adopt a traditional training program aimed at optimization of aerobic capacity should be firmly resisted.

Activity must be started slowly and at low enough levels so as not to exacerbate fatigue, pain or other symptoms. It will be intermittent, brief, spread throughout the day and followed by rest. Therapists can help patients understand that

activities of daily living reduce the energy available for other tasks. On busy days, patients may need to reduce other activities that day.

Patients who are caught in the “push-crash” cycle will likely need encouragement to reduce their activity levels at first. Initially, they should limit themselves to the basic activities of daily living—getting up, personal hygiene, dressing, essential tasks—until they have stabilized. Several daily sessions of brief, low-impact activity can then be added, such as one to three minutes of stretching, strength exercises or light aerobic activity (e.g., walking or cycling). These sessions are slowly increased (e.g., one to five minutes a week) as tolerance develops over two to six months. Daily exercise may be divided into two or more sessions to avoid symptom flare-ups. Intensity should not be the main focus of an exercise program; aim for a rate of perceived exertion between 9 (“very light”) and 12 (“somewhat hard”) on the Borg scale.

If patients experience an exacerbation in symptoms, they should return to the most recent manageable level of activity. Incorporating pacing, which allows patients to temporarily reduce their activity levels if they experience an exacerbation of fatigue or other symptoms, appears to be a beneficial addition to the traditional graded activity regimen.

Because a major CFS symptom is exacerbation of illness after even minimal physical or mental activity, including standard physical therapy programs, many patients believe that exercise aggravates the underlying disease process and thus believe they must avoid activity. Reports of typical exercise programs, which are based on programmed, regular exertional increases, have made some people with CFS reluctant to initiate graded activity therapy. In these cases, therapists can provide encouragement to patients, assuring them that the therapy’s purpose is to reduce (not exacerbate) symptoms and improve function, and that the pace will be slow and based upon their individual tolerances and abilities. In the clinical setting, CFS graded exercise programs require both consistency and flexibility to be successful.

Strength and Conditioning

The goals of the strength and conditioning program for CFS management are similar to those of graded activity: improved strength and flexibility, reduced pain, better function and quality of life, greater mental clarity and a sense of accomplishment and control over symptoms. Standard rehabilitative methods, such as resistance training and flexibility exercises, are potentially useful in improving stamina and function.

Activity begins slowly with simple stretching and strengthening exercises, using only the patient’s body weight as resistance. Patients must be closely monitored at first to make certain activity is not exacerbating symptoms. The goals are to

promote increases in strength and range of motion, geared toward improving the ability to engage in activities of daily living.

Examples of functional exercises include repeated hand stretches, sitting and standing, or picking up and grasping objects. Patients might begin with one set of two to four repetitions, building to a maximum of eight repetitions. Focused breathing periods help facilitate recovery and strengthen the muscles of respiration. Each set should be followed by a rest break that lasts three times as long as the time it took to complete the set. Once this stage is mastered, resistance band exercises can be added to build strength and flexibility. The same principle of brief intervals of exercise, followed by adequate rest, applies to this stage. Interval training using a heart rate monitor and self-ratings of perceived exertion provides quantifiable feedback and teaches the person with CFS what level of exertion they can do to avoid postexertional malaise. As function improves, independence from the therapist is encouraged through education of the client about the safe and effective maintenance of these strategies in a home-based program.

Energy Management

Energy management programs, such as pacing and envelope theory, are based on the theory that people with CFS have finite levels of energy, and learning to live within their activity limits will avoid exacerbating symptoms. The underlying premise is that, by managing energy wisely, available energy will increase over time.

- **Activity Pacing** - Activity pacing involves moderating activity to minimize the push-crash cycle and its consequences of more stress, discouragement and frustration. Patients are advised to do specific activities, such as household tasks, in small, manageable portions with rest breaks, rather than in a single energy-depleting effort. Activity should be intermittent, spread evenly throughout the day, and should not cause an exacerbation of fatigue or other symptoms. To help sustain healthy pacing of activity levels, it is important to address patient self-criticisms of laziness and guilt, fears of increased disability and discouragement over the loss of pre-illness abilities. Once patients are stabilized, activity is incrementally increased.
- **Envelope Theory** - Envelope theory instructs people to view their available energy as though it were a bank account. If they overexert themselves, it is like being overdrawn at the bank and they have to pay it back by resting more the next day. Pacing also teaches that certain foods or stressful situations tap energy reserves in a similar manner as physical or mental activity. People are taught to adjust their activity as needed, based on individual preferences, needs and circumstances. As time

passes, patients learn how much energy they can expend without experiencing the characteristic postexertional exacerbation of symptoms.

These methods tend to be supported by patients, even though there has been little formal research into their efficacy. The combination of pacing and graded activity/exercise, which allows patients to temporarily reduce their activity levels if they experience an exacerbation of fatigue or other symptoms, appears to be a beneficial combination for CFS patients.

Exercise Principles

- Start slowly and increase slowly, gradually increase both the level of activity and the duration.
- All exercise needs to be followed by a rest period at a 1:3 ratio, resting 3 minutes for each minute of exercise. Some patients can exercise for remarkably short periods, just 2-5 minutes, without risking a relapse.
- Limit deconditioned patients to the basic activities of daily living until they have stabilized. Several daily sessions of brief, low-impact activity can then be added, such as a few minutes of stretching, strength exercises or light activity like walking or cycling. These sessions are increased by 1-5 minutes a week as tolerance develops.
- Advise patients to return to the most recent manageable level of activity if they report that exercise is worsening symptoms. Daily exercise may be divided into two or more sessions to avoid symptom flare-ups; some patients, however, cannot exercise daily early in the course of their rehabilitation

Cognitive Behavioral Therapy (CBT)

CBT Overview

Cognitive behavior therapy (CBT) is an individualized form of therapy that is based on each individual's illness experience and the impact that it has on the person's life. Working with a CBT therapist, the person can examine beliefs, concerns and coping behaviors and modify these as necessary to develop constructive coping strategies. CBT is an effective part of the management of chronic diseases such as cancer, rehabilitation of orthopedic injuries, and depressive disorders.

The goal of CBT is to help the patient understand their illness and to change perceptions, beliefs and behaviors that can contribute to the impact of symptoms. CBT is an important adjunctive therapy in many medical conditions, including cardiovascular disease, diabetes and cancer, and is central to therapy for many mental health conditions, such as depression and anxiety. Optimally, CBT results in better adaptation to illness and improved quality of life. Controlled clinical trials

in CFS have shown that CBT can improve fatigue and activity levels, but has less impact on other symptoms.

For people with CFS, CBT is designed to promote a balance between activity, rest and leisure. People with CFS generally try to do more than they can capably manage without exacerbating symptoms. Specifically, the “push-crash” cycle in which they do too much, crash, rest, start to feel a little better, do too much once again, and so on. The techniques of CBT are intended to constructively alter this detrimental cycle.

Some people with CFS are reluctant to engage in CBT because they perceive that a psychological treatment will be ineffective for their physical illness, or that exercise will aggravate their symptoms and should therefore be avoided. In these cases, it can be explained to the patient that lifestyle and stress can influence physical symptoms and illnesses. Health care professionals can assist patients in understanding the principles of CBT, including its successful application in treating other medical conditions. However, if patients are actively resistant to CBT, it should not be forced upon him/her.

Additional Information about CBT

- All people monitor, in their brains, the biochemical signals that reflect ongoing bodily processes. Responses to these signals occur at both conscious and unconscious levels. When the conscious responses prevail, they may be either helpful or harmful. CBT assists the patient in responding to the illness in a positive manner. The short-term studies of CBT in CFS show improvement in function and symptom management. Some people studied to date also showed limited effect on pain and fatigue. It is not known if CBT will eventually be able to alleviate all symptoms for all people with the illness. The utility of CBT for CFS is in its formative stages and much needs to be learned before the full extent or limits of its usefulness are known.
- Psychiatric factors are relevant to any illness process. CBT has been shown to help patients deal with these factors and better cope with the life-altering issues of chronic illness. Awareness of the role that stress can play in exacerbating the symptoms of CFS is essential. CBT assists patients to recognize and more successfully manage stressors in their lives.
- CBT often involves the introduction of very slowly increased physical activity. Prescribed activity is individualized for the patient, based on present activity tolerance. Even people with extremely limited tolerance can be helped to gradually achieve increased strength and conditioning. People accustomed to “boom or bust” cycles in which they engage in a great deal of activity when feeling well and able, then followed by

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exhaustion, may need to curtail activity and more evenly pace exertion from day to day.

- The patient must be an active participant to receive the potential benefits of CBT. It is useful to educate the patient about the goals of CBT. Developing an individualized treatment plan can also be useful; it emphasizes the positive philosophy of the therapy.
- Careful patient adherence to CBT protocol is critically important to successful therapy. For CFS patients, increased symptomatology is the main reason cited for discontinuing CBT. Again, this may be avoided if a paced, personalized plan is followed and activities are tailored to the individual's capabilities. A skilled professional can assist in setting and reaching realistic goals.
- CBT patients need to take personal responsibility for change. Health care professionals can encourage the patient's capacity for change and recognize potential barriers to therapy.
- Multiple and varied biopsychosocial factors impact illness expression in patients and in their acceptance and readiness for therapy, including CBT. The rehabilitation professional can act to encourage use of this mode of therapy when appropriate and assist the patient in locating accurate information on this treatment method.
- CBT requires special training and must be administered by a skilled specialist. It should be noted that psychologists are not the only health care professionals that can successfully guide CBT. Nurses, physical therapists and occupational therapists are examples of multidisciplinary professionals who can be trained to conduct CBT. When treating CFS patients, the CBT therapist needs to be familiar with CFS, be aware of the evidence for CFS as a biologically based disorder and validate the patient's experience of living with a misunderstood illness.
- The Association for the Advancement of Behavior Therapy, available at www.aabt.org, or the National Association of Cognitive Behavioral Therapists, available at www.nacbt.org, may be able to assist in finding a trained professional in your area. Contacting local mental health professional groups or health care organizations may be helpful as well.
- Because CBT is often not covered by insurance, some CFS patients will not have access to formal therapy. In this situation, practitioners who understand CFS can provide information about the illness in general, lead individual patients to understand how their behavior is impacting the illness, and set up activity and exercise programs that are therapeutic.

Other Therapies

Counseling

A supportive counselor can help patients develop effective coping skills to manage the prospects of long-term illness, as well as family issues, anxiety, depression, grief, anger and guilt that frequently accompany any chronic illness. These problems can be addressed by a competent therapist using problem-solving techniques and standard psychotherapy and counseling methods.

Support Groups

Many people with CFS report that support groups can help fulfill their needs for information and a sense of community (Afari and Buchwald, 2003). Health care professionals can encourage their patients to seek out support groups with a positive focus.

Chronic Fatigue Syndrome (CFS) patients may find it therapeutic to meet with other people who have this illness, and often this can be accomplished by joining a local CFS support group.

Support groups are not appropriate for everyone, and some CFS patients may find that a support group actually adds to their stress rather than relieving it. Most support groups are free, collect voluntary donations, or charge modest membership dues to cover basic expenses (e.g. refreshments at meetings or photocopying costs).

A useful support group should include:

- Both newcomers and patients who have had CFS for longer periods of time to provide a balance of perspectives for the group.
- People with whom the CFS patient feels comfortable.
- Leaders who empathize, gently draw out shy members, and keep others from dominating, and who distill discussion into useful information.
- A history indicating the group is stable and meeting the needs of its members.

Some support groups may put their own interests before those of the individual patient. Groups that engage in any of the following activities should be avoided:

- Promise sure cures and quick solutions.
- Conduct meetings that are mainly "gripe" sessions.
- Urge patients to stop prescribed treatment and recommend a single solution to their problem.
- Insist that patients reveal private or sensitive information.
- Demand allegiance to a cult-like, charismatic leader.

- Charge high fees.
- Require patients to purchase products.

Diet and Nutrition

Good diet and nutrition can contribute to a successful activity management plan. Many CFS patients do not have the energy to prepare nutritious meals, leading to a poor diet that can contribute to fatigue. Additionally, decreased activity levels that are common in people with CFS mean patients typically expend less energy in a day. Unless caloric consumption is adjusted, weight gain can occur, further exacerbating fatigue and other symptoms.

- Encourage a well-balanced diet to prevent nutritional deficiencies and weight fluctuation and to reduce diet-related fatigue.
- Advise patients who have sensitivities to various foods or chemicals to avoid or reduce their exposure. Sensitivities to refined sugar, caffeine, alcohol and tobacco appear to be common in CFS patients.
- Educate patients that nutritional supplements cannot take the place of good diet and nutrition.

Nutritional supplements and vitamins have been cited as the second most widely used category of pharmacotherapy agents by people with CFS. Other studies have investigated or reported the use of supplements, including NADH, high-dose vitamin B12, essential fatty acids, magnesium, vitamin C, coenzyme Q10, echinacea and ginseng. These studies show inconsistent results, but symptom improvement was reported in some. Because these products are unregulated, quality, potency, dosage and information on side effects is frequently unknown. The health care professional needs to question patients regarding supplement use, including dosages, to determine interactions with prescription medications or possible contributions to symptoms. Patients should be informed of potentially dangerous interactions. One example of a serious interaction is the possibility of lowered serum potassium when the herbal supplement licorice root is taken with fludrocortisone.

Alternative Therapies

Alternative medicine is a choice for many people with CFS when symptom improvement has not occurred with traditional medicine. Yoga, massage, acupuncture and Tai Chi are among the therapies that have been evaluated in CFS or related conditions, and found to be of help for some patients.

A 2004 study by Weatherly and associates found “weak but equivocal evidence that the effects of homeopathic medicine are superior to placebo” for treatment of Chronic Fatigue Syndrome.

Prognosis

Very few studies have attempted to follow the long-term course of CFS in defined populations outside of specialty referral clinics. A relapsing-remitting pattern and changes in symptoms, and their individual severity, is common. There is great individual variation in the course of illness, ranging from worsening symptoms to substantial recovery and many people experience improved function over time, allowing them to increase their work or other activities even though they continue to experience symptoms.

Most data on prognosis comes from tertiary or specialty care centers, which generally see the sickest patients, and there is some suggestion that CFS patients cared for by primary care professionals have a better prognosis. Clinical research suggests that younger age at onset, shorter duration of illness, milder fatigue and absence of comorbid psychiatric illnesses lead to better prognosis. Clinical experience suggesting that earlier diagnosis leads to better outcomes awaits formal testing. However, improvement is possible in any individual patient at any point in the course of the illness. More study is needed to understand predictors for recovery

Disability

By definition, all people with chronic fatigue syndrome (CFS) are functionally impaired, and studies have shown that approximately one-third of these people are unable to maintain full-time employment after becoming ill. Some are able to continue to work full time; some are able to work only part time; and numerous others are unable to work at all.

Work is a source of identity and self-esteem for many people, and the inability to work can have negative health consequences. Some people have difficulty accepting that they may have to discontinue working and rely upon insurance companies, government or family for financial support. People grieve the loss of independence, financial security, self-sufficiency, social connectedness and sense of productivity that come with employment.

The application process for disability benefits is often protracted and frustrating. In order to demonstrate their need for benefits, applicants must identify all the things they are now incapable of doing. Admitting their weaknesses and limitations can be emotionally difficult. Completing the application forms and gathering the information necessary to justify their application is a physically, cognitively and mentally draining process. Many applicants may choose to hire an attorney or rely on the assistance of a trusted family member or friend to help them through the process. If your patient is represented by an attorney in disability matters, it is advisable to obtain a release form from the patient allowing you to communicate with the attorney.

Documentation Fundamentals

Treating health care professionals are a major source of pertinent information required for the disability application. All members of the health care team can contribute useful information. For example, referrals to rehabilitation and physical therapists can provide constructive approaches that maximize medical improvement and assist with disability documentation. Information from relatives, friends, counselors, therapists and others can be used to illustrate the severity and nature of the patient's impairments, as long as they are recorded by the treating physician and the information is justifiable and credible. Also, the patient or family may be able to provide a diary or summary of typical daily activities. Patients' journals are also considered pertinent evidence.

It is helpful to record supportive medical signs such as swollen or tender lymph nodes, pharyngitis and persistent reproducible muscle tenderness (e.g., the tender points of fibromyalgia). Abnormalities in MRI, orthostatic dysfunction by tilt-table testing, abnormal sleep studies, mental status or neuropsychiatric testing or functional capacity examinations can support functional impairment.

The process of preparing letters or reports or filling out forms can be time-consuming, but may be streamlined by maintaining adequate documentation, keeping detailed office notes and following an outline. Documentation needs to be as complete and specific as possible.

Impairment

Impairments might include increased fatigue with physical or mental exertion (limits ability to function on a regular and sustained basis), pain (reduces mobility) and difficulty with concentration, comprehension of new information, recall or memory tasks and executive function (making calculations, handling money) or difficulty in driving. These may be documented by contemporaneous office notes detailing symptoms, treatments and how these impairments impact the patient's activities of daily living and work. Next, it is necessary to establish that these impairments prevent even sedentary and light activities on a regular, predictable or sustained basis. Lastly, the health care professional must generally predict, based on experience and the patient's response to therapy, how long impairments would be expected to last.

Measurement of Disability

Bell's Disability Scale provides a numerical representation of an individual's severity of symptoms, degree of activity impairment and ability to function in full-time work. Although not scientifically validated, this tool was designed for ease of use in the clinical setting to help document status from visit to visit.

Bell's CFS Disability Scale

The attempt is to document as accurately as possible the severity of symptoms, the degree of activity impairment with both activity and rest, and the functional ability regarding full-time work.

- 100** No symptoms at rest. No symptoms with exercise; normal overall activity level; able to work full-time without difficulty.
- 90** No symptoms at rest; mild symptoms with activity; normal overall activity level; able to work full-time without difficulty.
- 80** Mild symptoms at rest, symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.
- 70** Mild symptoms at rest; some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full-time with difficulty.
- 60** Mild to moderate symptoms at rest; daily activity limitation clearly noted. Overall functioning 70%–90%. Unable to work full-time in jobs requiring physical labor, but able to work full-time in light activities if hours flexible.
- 50** Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duty or deskwork 4–5 hours a day, but requires rest periods.
- 40** Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 50%–70% of expected. Not confined to house. Unable to perform strenuous duties; able to perform light duty or deskwork 3–4 hours a day, but requires rest periods.
- 30** Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform deskwork 2–3 hours a day but requires rest periods.
- 20** Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 30%–50% of expected. Unable to leave house except rarely; confined to bed most of day; unable to concentrate for more than 1 hour a day.
- 10** Severe symptoms at rest; bedridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.
- 0** Severe symptoms on a continuous basis; bedridden constantly; unable to care for self.

Additional Disability Information/Resources

Disability Evaluation Under Social Security

www.socialsecurity.gov/disability/professionals/bluebook/index.htm

Evidentiary Requirements for Medical Professionals Under Social Security Blue Book

www.socialsecurity.gov/disability/professionals/bluebook/evidentiary.htm

Disability Evaluation in a Nutshell: A Three-Minute Guide to Effective Medical Reports

This 16-page booklet includes SSA listing of impairments (adult categories), an example of a hypothetical medical professional's report and a "doctor's checklist for functional impairment.

www.cfids.org/ecommerce/products.asp?setCategory=21

Physicians Disability Service (PDS):

This attorney-developed website offers materials on various disability issues.

www.disabilityfacts.com

American Academy of Disability Evaluating Physicians

Activities include: 1) ongoing teaching of the management of disabled patients; 2) teaching impairment and disability evaluation to physicians, other health care providers, attorneys, regulators, legislators and others involved in the care of the disabled; and 3) coordination of research in the area of disability management.

www.aadep.org

Impact of CFS

CFS has wide-ranging effects on patients, their families, friends, employers, coworkers and society, the most common of which are described below. People with other chronic, debilitating conditions may experience these same effects. The overall treatment plan should acknowledge these life-altering changes and the patient's emotional reactions to them.

Patients

CFS has a variety of effects on people who have it. Common difficulties include problems coping with the debilitating, variable and unpredictable symptoms; decreased stamina; difficulties with memory and information processing; uncertain prognosis; loss of independence, livelihood and economic security; alterations in relationships with family and friends; and feelings of isolation and abandonment. All of these issues can add to existing stress, which can exacerbate the symptoms of CFS.

People with CFS may feel traumatized and stigmatized because family, friends, medical professionals, employers, coworkers and others do not recognize the seriousness or magnitude of their symptoms. Some people with CFS report expending considerable time and energy proving or justifying their illness and impaired function. Patients may also worry about bearing and raising children and the potential impact of decreased sexual activity on intimate relationships.

Family Members and Friends

Chronic illnesses such as CFS affect not only the individual, but family members, caretakers and friends as well. Health care professionals should be alert to such family problems. These problems may be particularly important in CFS because healthy people find it hard to understand the variability of symptoms and unpredictability of function, particularly since there are no overt, visible signs of illness. CFS may cause a person to cancel plans or fall behind on duties or obligations, leading to further frustration and anger among family members and friends.

Children of people with CFS can be deeply affected by a parent's illness. Common issues include fear that the parent will die and abandon them, frustration or embarrassment that the parent is not like friends' parents, and concerns about genetic risk or contagion. In families with an adult ill with CFS, health care professionals need to be aware of the impact on the child's health and the potential projection of the adult's illness onto the child. Healthy siblings of youth with CFS can feel that the person with CFS receives a disproportionate amount of the family's attention or that they are expected to carry a greater share of the family's load.

Consults with behavioral health professionals may be necessary to assist with identification and therapeutic interventions for underlying family problems that contribute to symptoms or that result from having a sick child or adult in the family. Recognition of these problems is key to instituting appropriate care management. The health care professionals can encourage all family members to participate in behavioral therapy programs to better understand family dynamics related to living with CFS.

Employers and Coworkers

Frequent absences, uncompleted obligations, problems with memory and concentration, increased errors due to cognitive impairment, decreased physical and mental stamina, and escalation of pain can cause problems for the person with CFS in the workplace. The lack of obvious physical signs of illness can lead to accusations that the person with CFS is fabricating symptoms to avoid responsibilities. Finally, accommodations by the employer may cause resentment, misunderstandings and claims of special treatment by coworkers.

Although federal laws protect the rights and jobs of the disabled who are able to perform their essential job functions, the emotional and social aspects of a person with an “invisible” disability in the workplace are not addressed by the legal system.

Coping with CFS

Living with chronic fatigue syndrome can be difficult. Like other debilitating chronic illnesses, CFS can have a profound impact on daily life, requiring patients to make significant lifestyle changes and adapt to a series of new limitations.

Common difficulties for CFS patients include problems coping with:

- the severe, changing and unpredictable symptoms of varying severity
- a decrease in stamina that interferes with activities of daily living
- memory and concentration problems that seriously impact work or school performance
- an uncertain prognosis that makes it hard to plan for the future
- loss of independence, livelihood and economic security
- alterations in relationships with family and friends
- worries raising children
- concerns about the potential impact of decreased sexual activity on intimate relationships
- skepticism and misconceptions about the illness

Feelings of anger, guilt, anxiety, isolation and abandonment are common in CFS patients. While it's normal to have such feelings, unresolved emotions and stress can make symptoms worse, interfere with pharmacological therapies and make recovery harder. It's important for patients to acknowledge the life-altering changes imposed by their illness and to develop effective coping strategies to deal with these changes.

Children and Adolescents

Adolescents may also develop CFS, although the occurrence in adolescents is rare. In general, a diagnosis of CFS is not appropriate for children under age 12. The 1994 definition was designed to identify adults with the syndrome, and while these criteria are applied to adolescents, they may not be entirely adequate in assessing CFS in younger people. The unique aspects and challenges of chronic illness (including CFS) in adolescents warrant special mention and should be considered by health care professionals who care for this age group.

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- Young people may not report medical information the same way adults do. They may use different words to describe their symptoms or may not have a complete understanding of their symptoms or emotions. Some ill youth may lack a sense of “normal” and may not perceive their symptoms as indicative of an illness process.
- Parents or guardians may be the main source for reporting health information. Adults’ observations may differ from the feelings and experiences of the child or adolescent.
- Damaged social relationships and isolation are common consequences of chronic illness in youth and this is particularly problematic in adolescence. Efforts should be made to help the adolescent build and maintain relationships with peers and participate in enjoyable, age-appropriate activities.
- School absenteeism — particularly in the early stages of illness — is common among children and adolescents with CFS. Absenteeism combined with problems in memory and concentration that accompany CFS can result in delayed educational progress.
- Students with CFS typically do not qualify for educational accommodations under the Individuals with Disabilities Education Act or the Rehabilitation Act. Health care professionals can help schools and families work together to develop appropriate educational plans for students with CFS. These may include reduced schedules, home tutoring, alternative test-taking conditions and counseling. The need for and effectiveness of alternate educational strategies should be reviewed regularly because the goal of therapy is return to full participation (academically, developmentally, socially, intellectually); as this is achieved, alternative education is not only no longer necessary, but may complicate full development.

Conclusion

CFS is a complex condition of considerable public health importance. CDC studies document that it affects more than one million American adults and that these people may be more severely impaired than those with cancer, end-stage renal disease, heart disease or multiple sclerosis. As noted previously, at least 25% of those suffering from CFS are unemployed or receiving disability because of the illness. CDC has estimated that the average family affected by CFS forgoes almost \$20,000 annually in lost earnings and wages and that CFS costs the U.S. \$9.1 billion per year in lost productivity. Costs related to health care utilization and disability benefits paid by Social Security and private insurers were not factored into this estimate. Therefore, the total costs of CFS to the U.S. economy are significantly higher.

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Clearly, CFS is a complex illness with symptoms that are common to other diseases. Nevertheless, the process of sorting through symptoms and assessing abnormalities (by a thorough history and physical) is no different from clinical assessment of other illnesses. Like other illnesses, CFS symptoms form a specific pattern that, when combined with exclusionary laboratory tests, are diagnostic.

Health care professionals and patients can partner to develop treatment plans that improve function and reduce symptom impact. And, through a mutual exchange of information it may be possible to discover undetected, treatable causes of symptoms and illness consequences. This patient/provider partnership may produce beneficial outcomes, including an enhanced quality of life for the patient and a rewarding experience for the health care professional.

Diagnosing and managing CFS can be a challenge but it is not impossible. Rigorous research is being conducted into its causes and treatment, and there are many public and private organizations that provide necessary support for further research and education of health care professionals. These efforts provide hope for people afflicted with this illness and the health care professionals who are responsible for their care.

Appendix A

Assessment Instruments

Recommended assessment instruments include the CDC Symptom Inventory, SF-36 and MFI-20, which are comprehensive and scientifically validated instruments that provide documentation of the illness. These tools may be considered more appropriate by providers who need a more in-depth assessment. The Multidimensional Fatigue Inventory (MFI) is a 20-question survey that assesses the physical, psychosocial and cognitive impact of fatigue on perceived quality of life over the prior month.

The Visual Analog Pain Scale is a widely accepted and used tool, as are verbal rating scales and the Wong-Baker FACES Pain Rating Scale.

CDC Symptom Inventory

The CDC Symptom Inventory for clinical application addresses the presence of the eight case-defining CFS symptoms and their magnitude and frequency. A research version contains 21 items, which address the eight case definition symptoms as well as eleven other commonly reported symptoms.

The full-text research study is available online at

www.pophealthmetrics.com/content/3/1/8

To download the clinical version of the CDC Symptom Inventory visit

http://www.institutferran.org/documentos/cdc_full_symptom_inventory.pdf

SF- 36 Health Assessment Tool

The SF-36 is a multi-purpose, short-form health survey with only 36 questions. It yields an 8-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index. It is a generic measure, as opposed to one that targets a specific age, disease or treatment group. The item is available for clinical and academic use as the Rand-36 and is available at:

www.rand.org/health/surveys_tools/mos/mos_core_36item.html

Questionnaire:

www.rand.org/health/surveys_tools/mos/mos_core_36item_survey.html

Scoring rules:

www.rand.org/health/surveys_tools/mos/mos_core_36item_scoring.html

Multidimensional Fatigue Inventory (MFI-20)

The Multidimensional Fatigue Inventory (MFI-20) is a 20-item self-report instrument consisting of five scales: General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation, and Mental Fatigue. Each scale contains four items rated on a scale of zero to 5 with the scale score of zero having the anchor of

entirely true and the scale score of 5 having the anchor of no, not true. The five scales were identified through factor analysis and are assumed to measure different aspects of fatigue. For information on acquiring the MFI-20, contact meded@cfids.org

Scales

Visual Analog Scale

None		Mild		Moderate		Severe		Worst possible		
0	1	2	3	4	5	6	7	8	9	10

The Wong-Baker Faces Pain Rating Scale

Designed for children aged 3 years and older, the Wong-Baker Faces Pain Rating Scale is also helpful for people who may be cognitively impaired, the elderly or those with a language barrier. It offers a visual description rather than verbal.



Other validated assessment tools assess specific symptoms such as sleep problems or depression. Examples are as follows:

Beck Depression Inventory

The original, scientifically validated Beck Depression Inventory tool was developed in 1961. An updated version of the tool was created in 1996 to better reflect DSM-IV criteria (Beck Depression Inventory®-II)(BDI®-II, Beck AT, Steer RA, Brown GA).

The BDI-II consists of 21 items to assess the intensity of depression in clinical and normal patients. Each item is a list of four statements arranged in increasing severity about a particular symptom of depression.

A sample of the Beck Depression Inventory can be viewed at:
www.ibogaine.desk.nl/graphics/3639b1c_23.pdf

The instrument can be ordered from the Harcourt Assessment website,
http://harcourtassessment.com/haiweb/cultures/en_us/productdetail.htm?pid=015-8018-370

PHQ-9

The PHQ-9 is a validated assessment instrument comprised of the nine signs and symptoms of depression in the DSM-IV with a question on functional impairment from the symptoms (as also required in the DSM-IV). The MacArthur Foundation Initiative on Depression and Primary Care has created a Depression Tool Kit, which is intended to help primary care clinicians recognize and manage depression. The Tool Kit includes easy-to-use instruments and information sources and is free of charge.

The kit is available at:

www.depression-primarycare.org/clinicians/toolkits/materials/forms/phq9/

Pittsburg Sleep Quality Index

The Pittsburg Sleep Quality Index (PSQI) is a reliable and validated self-rated questionnaire that provides an index of sleep quality. The PSQI includes 19 self-rated questions, which are grouped into seven component scores. The research article describing this tool is available at www.sciencedirect.com

A sample of the Pittsburg Sleep Quality Index (PSQI) can be viewed at:

www.cs.nsw.gov.au/rpa/sdc/source/PITTSBURGH%20SLEEP%20QUALITY%20INDEX.pdf

Borg Rating of Perceived Exertion (RPE) Scale

The Borg rating scale ranges from 6 to 20, where 6 means "no exertion at all" and 20 means "maximal exertion." The patient chooses the number that best describes their level of exertion. This will objectify the intensity level of the patient's activity, and the therapist can use this information to accelerate or decelerate activity levels to reach the desired range.

The patient should appraise their feeling of exertion as honestly as possible, without thinking about what the actual physical load is. Their feeling of effort and exertion is important, and it should not be compared to the level of others.

Borg RPE Scale

- 6 No exertion at all
- 7 Extremely light
- 8
- 9 Very light (*For a healthy person, it is like walking slowly at his or her own pace for some minutes*)
- 10
- 11 Light
- 12
- 13 Somewhat hard (*exercise, but it still feels OK to continue*)
- 14
- 15 Hard (heavy)
- 16
- 17 Very hard (*can still go on, but really has to push himself. It feels very heavy, and the person is very tired.*)
- 18
- 19 Extremely hard (*For most people this is the most strenuous exercise they have ever experienced.*)
- 20 Maximal exertion

Tools to Measure Functional Ability

There are a few brief screening instruments that can help monitor a patient's functional status and eligibility for disability benefits. Although not scientifically validated, these tools were designed by practitioners for ease of use in the clinical setting to help document status from visit to visit. Bell's Disability Scale provides a numerical representation of an individual's severity of symptoms, degree of activity impairment and ability to function in full-time work (Bell, 1995). The Subjective Functional Capacity Assessment (Lapp, 1993) is a helpful measure of the functional impact of fatigue.

Bell's CFS Disability Scale

This scale was developed to document as accurately as possible the severity of symptoms, the degree of activity impairment with both activity and rest, and the functional ability regarding full-time work.

100 No symptoms at rest. No symptoms with exercise; normal overall activity level; able to work full-time without difficulty.

90 No symptoms at rest; mild symptoms with activity; normal overall activity level; able to work full-time without difficulty.

80 Mild symptoms at rest, symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.

70 Mild symptoms at rest; some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full-time with difficulty.

60 Mild to moderate symptoms at rest; daily activity limitation clearly noted. Overall functioning 70%–90%. Unable to work full-time in jobs requiring physical labor, but able to work full-time in light activities if hours flexible.

50 Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duty or deskwork 4–5 hours a day, but requires rest periods.

40 Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity; overall activity level reduced to 50%–70% of expected. Not confined to house. Unable to perform strenuous duties; able to perform light duty or deskwork 3–4 hours a day, but requires rest periods.

30 Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform deskwork 2–3 hours a day but requires rest periods.

20 Moderate to severe symptoms at rest. Severe symptoms with any exercise; overall activity level reduced to 30%–50% of expected. Unable to leave house except rarely; confined to bed most of day; unable to concentrate for more than 1 hour a day.

10 Severe symptoms at rest; bedridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.

0 Severe symptoms on a continuous basis; bedridden constantly; unable to care for self.

This scale is from *The Doctor's Guide to Chronic Fatigue Syndrome*, by David S. Bell, MD, pages 122-123. Addison-Wesley Publishing Company, Reading, MA. Copyright © 1994, 1995.

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Subjective Functional Capacity Assessment Tool

Please circle the best response for each activity described below:

Activities of Daily Living

1. Need some assistance
2. Slight difficulty
3. Minimal difficulty
4. No problem

Grocery Shopping

1. Unable
2. Occasionally
3. Frequently, but with assistance
4. No problem

Laundry

1. Unable
2. Occasionally
3. Regularly in small steps or with help
4. Regularly without help

Social Activities

1. Unable
2. Infrequently
3. Occasionally
4. Frequently

Cooking

1. Unable
2. Take-out, simple breakfast or lunch
3. Simple microwave or crockpot meals
4. Regular meal preparation

Driving

1. Unable
2. Rarely
3. Cautious, local trips
4. Distant trips or traffic

Housekeeping

1. Unable
2. Light
3. Regular chores; small steps or with help
4. Regular

Errands or Light Chores

1. None
2. 0-1 per day
3. 1-2 per day
4. Few restrictions

*Please indicate for how long you can perform the following activities on a typical day:
(Total amount of time each day, with rest periods as necessary)*

	Not at all	15 min	30 min	1 hr	1-3 hrs	>3 hours
Sedentary (sitting, watching TV)	1	2	3	4	5	6
Light Activity (eating, small crafts)	1	2	3	4	5	6
Moderate activity (tidy room, fix meal)	1	2	3	4	5	6
Heavy activity (vacuum room, rake yard)	1	2	3	4	5	6

Source: Charles W. Lapp, MD. Hunter-Hopkins Center, Charlotte, NC

Innovative Educational Services

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Other Useful Assessment Tools

DePaul Pediatric Health Questionnaire (DPHQ)

The DePaul Pediatric Health Questionnaire (DPHQ) is used among children who are under the age of 18 years old. It can be administered to 12 -17 year olds as a self-report or for children younger than 12 years old, an adult guardian should fill out the questionnaire along with the child.

A sample of the DPHQ is available at:

<http://www.iacfsme.org/Portals/0/pdf/DePaulPediatricHealthQuestionnaire.pdf>

DePaul University Fatigue Questionnaire

The DePaul University Fatigue Questionnaire was developed for clinicians and researchers to administer to their patients as a screening instrument for CFS. The Questionnaire is comprehensive, covering the inclusionary and exclusionary self-report criteria of the current U.S. case definition. The instrument also assesses past and current activity levels, and symptoms of post-exertional malaise to ensure these items are adequately assessed.

A sample of the DePaul Fatigue Questionnaire is available at:

<http://www.iacfsme.org/Portals/0/pdf/kingquestionnaire.pdf>

Supplemental Information

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Chronic Fatigue Syndrome

Post-Test

1. Which of the following statements is TRUE? (p. 4)
 - A. CFS occurs 2X more frequently in women than in men.
 - B. CFS occurs most often in people 20-39 years old.
 - C. CFS occurs in all races and ethnic groups around the world.
 - D. In the U.S., CFS occurs much more frequently in Caucasians than it does in African Americans or Hispanics.
2. CFS is caused exclusively by the Epstein-Barr virus. (p. 5) A. True B. False
3. Which case definition is the accepted standard utilized for CFS research studies? (p. 10-11)
 - A. CDC Definition
 - B. International (1994) Definition
 - C. Canadian Definition
 - D. International (2003) Definition
4. CFS symptoms vary from person to person in type, number and severity. (p. 13) A. True B. False
5. According to the Klimas & Lapp CFS Evaluation & Diagnosis Model, an individual must experience chronic fatigue for at least _____ to be diagnosed with Chronic Fatigue Syndrome. (p. 15-16)
 - A. 1 month
 - B. 3 months
 - C. 6 months
 - D. 9 months
6. Which of the following conditions does NOT exclude a diagnosis of CFS? (p. 19)
 - A. Narcolepsy
 - B. Hepatitis C
 - C. Severe obesity
 - D. Multiple Chemical Sensitivity Disorder
7. CFS often follows a cyclical course, alternating between periods of illness and relative well-being. (p. 19) A. True B. False
8. Which of the following is NOT a primary subjective complaint associated with CFS? (p. 20)
 - A. Cognitive dysfunction
 - B. Tinnitus
 - C. Joint and muscle pain
 - D. Sore throat
9. Healthcare professionals should assume that all people with CFS have depression. (p. 22) A. True B. False
10. Which of the following is NOT one of the validated instruments recommended by the CDC for the assessment of individuals with CFS? (p. 24-25)
 - A. Bartolone Functional Assessment
 - B. Medical Outcomes Survey Short Form - 36
 - C. CDC Symptom Inventory

CHRONIC FATIGUE SYNDROME

- D. Multidimensional Fatigue Inventory
11. Activity and symptom diaries may be very effective during early phases of the therapy process, but become less effective or more difficult to maintain during later phases of therapy. (p. 26)
A. True B. False
 12. One of the primary goals of exercise is to optimize aerobic capacity. (p. 27) A. True B. False
 13. Activity pacing is an energy management principle that involves moderating activity to minimize the push-crash cycle. (p. 30) A. True B. False
 14. Which of the following statements is TRUE regarding Cognitive Behavioral Therapy (CBT)? (p. 31-33)
 - A. CBT is a group form of therapy that is based on individual illness experiences
 - B. The goal of CBT is to help the patient understand their illness and to change perceptions, beliefs, and behaviors that can contribute to the impact of symptoms.
 - C. Cost is the main reason cited by CFS patients for discontinuing CBT.
 - D. Specially trained psychologists are the only healthcare professionals qualified to conduct CBT
 15. Which treatment is supported by strong scientific evidence demonstrating its effectiveness for significantly reducing CFS symptoms? (p. 35)
 - A. NADH
 - B. Coenzyme Q10
 - C. Homeopathic medicine
 - D. None of the above
 16. Approximately one-third of people with CFS are unable to maintain full-time employment after becoming ill. (p. 36) A. True B. False
 17. A person experiences moderate CFS symptoms at rest, and moderate to severe symptoms with exercise. They are able to perform deskwork for 4-5 hours per day, but require occasional rest periods. What would this person's score be utilizing the Bell's CFS Disability Scale? (p. 38)
 - A. 50
 - B. 40
 - C. 30
 - D. 20
 18. Feelings of anger, guilt, anxiety, isolation and abandonment are common in CFS patients. (p. 41) A. True B. False
 19. Students with CFS typically do not qualify for educational accommodations under the Individuals with Disabilities Education Act. (p. 42) A. True B. False
 20. Which one of the following is an appropriate and applicable assessment tool for a pediatric patient? (p. 44-49)
 - A. Wong-Baker Faces Pain Rating Scale
 - B. Bell's CFS Disability Scale
 - C. Subjective Functional Capacity Assessment Tool
 - D. Glickman ADL Survey

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