

# Chronic Fatigue Syndrome

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## Overview of CFS

Chronic fatigue syndrome is a debilitating and complex disorder characterized by profound fatigue of at least 6 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, post-exertional malaise, headaches, muscle pain, joint pain, sore throat and tender cervical/axillary nodes). These symptoms are discussed in detail in the "Recognition and Diagnosis" section of this course.

Most CFS patients who seek medical attention from physicians and other members of the health care community often describe their illness as beginning suddenly over a period of hours or days. In contrast, people with CFS who are identified in community studies more often report a gradual onset of illness over weeks or months. The clinical course of CFS 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. Other diseases that could explain the symptoms of CFS must be identified and treated before a patient's condition can be diagnosed as CFS. This tenet is particularly important for behavioral and rehabilitative therapists because they may see persons with illnesses similar to CFS who may not have received an adequate medical or psychiatric evaluation.

Various terms are often used interchangeably with CFS. CFS is the preferred term because it 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 does not currently exist. Chronic active Epstein-Barr virus (EBV) infection (chronic mononucleosis) was thought to be the cause of CFS during the 1980s, and this association is now known to be rare. However, post-infection fatigue syndromes have been associated with EBV and other infectious agents. 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:** Studies have found that 1%–2% of the general population suffers symptoms of CFS (Steele et al., 1998; Jason et al., 1999; Reyes et al., 2003; Bierl et al., 2004) and that CFS can be confirmed in between 0.24% and 0.42% of adults (Jason et al., 1999; Reyes et al., 2003). More importantly, studies in Chicago and Wichita documented that only 10%–16% of individuals with CFS have been diagnosed by or treated for CFS by a medical professional (Kennedy et al., 2000; Reyes et al., 2003). The low rate of diagnosis highlights the need for increased awareness of CFS by health care providers throughout the health care system.
- **Demographics:** Recent studies have shown that much of the CFS patient stereotype of the last two decades is incorrect. Both the Chicago and Wichita studies found CFS to be 3 to 4 times more common in women than in men and found that CFS is most common in the 40 to 60 year age-range (although people of all ages may develop the disorder). Both studies showed that CFS is significantly more common in persons with lower income levels. Finally, the studies also showed that non-Caucasian persons are as likely to have CFS as Caucasians. Studies currently underway will serve to update CFS demographics

## A Framework for Understanding CFS

Although CFS has been studied internationally for almost two decades, there are still many questions and few definitive answers. This uncertainty is often a source of stress and anxiety as patients seek to understand their illness and its impact. Considerable information about CFS is available, especially on the Internet, but it is often not credible or accurate. Health professionals participating in the care and rehabilitation of people with CFS can assist them in developing a

framework for understanding CFS, its contributing factors, possible causes and prognosis, all of which can facilitate feelings of control and hopefulness.

- **Causes and Contributing Factors:** 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. Explanations have included central nervous system aberrations, immune system dysfunction, infectious diseases, psychiatric disorders, stress, hormonal disturbances and cardiovascular aberrations (Afari and Buchwald, 2003). One current view is that CFS has a variety of predisposing or associated factors that result in a recognizable pattern of symptoms and impairment. Proponents of this view have sought to study the origins of CFS by using a biopsychosocial model in which the body and mind influence each other's function and activity. This model includes three general factors involved in the onset and clinical course of CFS:
  - **Predisposing/risk factors** are those that make a person more susceptible to CFS.
  - **Triggering factors** are those which, when experienced by a susceptible person, lead to the onset of CFS.
  - **Perpetuating factors** are those that delay or prevent improvement.

Essentially all studies have shown that women are more likely to develop CFS than are men. Physical and mental stress and acute infectious diseases have been associated with CFS, but the specific nature of their association (risk vs. triggering factors) is unknown. How risk factors impact responses to infections or other stressors that precede chronically fatiguing illnesses remains unclear. Finally, other conditions that occur in many individuals with CFS (e.g., sleep disorders, hormonal disturbances or psychiatric conditions) may represent co-morbid illness unrelated to CFS, may result from CFS, may be causally associated with risk of CFS or could share the same pathophysiologic pathways.

- **Effects of Exertion:** Exacerbation and prolonged duration of symptoms following physical or mental exertion is one defining symptom of CFS, is reported by most patients, and is of particular importance to those responsible for therapy and rehabilitation of persons with CFS. As discussed later in this text, carefully designed and supervised rehabilitative therapy is important in the care management of CFS patients. Patients can learn to modify their activities to avoid post-exertional malaise and therefore improve their health status and function. Post-exertional exacerbation of the illness must be considered when developing intervention strategies for people with CFS. It is essential that rest and activity are balanced to avoid both deconditioning from lack of activity and flare-ups of illness due to overexertion.

## Recognition and Diagnosis

Recognition and diagnosis of CFS can be challenging for health care practitioners. Fatigue is a common symptom of many illnesses; between 10 and 25% of all patients who visit general practitioners complain of prolonged fatigue (Hickie et al., 1999). Symptoms that comprise CFS are common in other conditions. However, there are distinct patterns and features of CFS that allow it to be differentiated from other medical and psychiatric conditions. Diagnosis of CFS can be made only after a thorough history, physical and mental status exam, and appropriate laboratory testing to rule out diseases that may be responsible for the patient's symptoms and for which specific treatment exists. CFS is essentially a diagnosis of exclusion.

Health care providers from multiple disciplines may encounter CFS patients at any point in the evaluation and management process. Rehabilitation and behavioral professionals may see undiagnosed CFS patients who are seeking evaluation and treatment of pain disorders, poor physical function and mental health conditions (e.g., depression or somatization disorder). These patients may also seek care to help them cope with interpersonal and lifestyle changes, lack of stamina or employment problems stemming from poor health. CFS patients may also have secondary mood symptoms, such as anxiety and depression, for which they seek evaluation and treatment. Patients who present with symptoms of CFS, but have not been evaluated, should be referred to a primary medical care provider.

### **CFS Case Definition**

The International Working Group Case Definition of CFS (Fukuda et al., 1994) and clarifications published in 2003 (Reeves et al., 2003) provide the current international standard for diagnosis of CFS in research studies and provide appropriate guidelines for clinical diagnosis. CDC has developed an empirical case definition that addresses diagnostic and assessment needs in both the research and clinical arenas (Reeves et al., 2005).

CFS has no characteristic physical signs or diagnostic laboratory abnormalities. Diagnosis of CFS involves careful evaluation of symptoms and ruling out or treating other causes of the patient's complaints. The diagnosis of CFS requires that patients report severe persistent or relapsing fatigue of at least 6 months duration.

This fatigue represents profound mental and physical exhaustion that is not relieved by rest. It is not the typical fatigue that people frequently experience after strenuous physical activity, a difficult workweek or other episodes of unusual stress. CFS must cause significant reduction in the patient's previous ability to perform one or more aspects of daily life (work, household, recreation or school). Those evaluating patients with CFS should remember that, in spite of their profound disability, many people with CFS do not appear physically ill. In addition to fatigue, the illness must include at least 4 of the 8 symptoms specified in *Table 1*. Most people with CFS report unusual post-exertional fatigue, unrefreshing sleep, and difficulty with memory/concentration; the other symptoms are reported by varying proportions of patients. Most CFS patients report that fatigue and other symptoms (especially concentration/memory problems and pain) are worsened by previously well-tolerated physical or mental activity.

CFS patients may report many other symptoms that are not part of the syndrome, such as allergies or sinus problems; numbness or tingling; feeling "in a fog;" dizziness and balance problems; sensitivity to substances and stimuli; and night sweats (Nisenbaum et al., 2004). Providers should investigate the possibility of underlying medical and psychiatric disorders in those patients who report numerous symptoms not strictly associated with CFS and should remain alert to the development of new symptoms that require further evaluation.

### Brief Overview of CFS Diagnosis

<p>Six or more months of unexplained, debilitating fatigue that is not alleviated by rest and results in substantial reduction in previous levels of occupational, educational, social or personal activities, PLUS 4 or more of the following:</p> <ul style="list-style-type: none"> <li>• Post-exertional malaise lasting more than 24 hours</li> <li>• Unrefreshing sleep</li> <li>• Impaired memory or concentration</li> <li>• Muscle pain</li> <li>• Multi-joint pain without redness or swelling</li> <li>• New headaches</li> <li>• Frequent, recurring sore throat</li> <li>• Tender cervical or axillary lymph nodes</li> </ul> <p>EXCLUDE a diagnosis of CFS if another medical or psychiatric condition that could explain symptoms is present, except:</p> <ul style="list-style-type: none"> <li>• Conditions which have been treated and resolved, according to the case definition guidelines</li> <li>• Conditions diagnosed based on symptoms, rather than laboratory tests</li> </ul> <p>(Ref.: Fukuda et al., 1994 and Reeves et al., 2003)</p>
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**Table 1**

- **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, 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. Examples 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 neurologic diseases (e.g., multiple sclerosis, neuromuscular diseases, epilepsy, stroke, head injury); 5) major endocrine diseases (e.g., adrenal insufficiency, hypopituitarism); and 6) primary sleep disorders (e.g., sleep apnea, narcolepsy).

Note that these conditions are considered exclusionary only in the research setting. In the clinical setting, patients must receive a careful medical evaluation searching for accompanying conditions; after appropriate treatment for these conditions, the clinical professional will determine whether the other disease is a major contributor to the patient's symptoms (Reeves et al., 2003).

Health care providers 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.

**CFS and Depression:** Depressive disorders frequently complicate care of patients with CFS. Twenty-five percent of CFS patients suffer a major depressive disorder, and 50% to 75% have experienced a depressive episode during their lifetime (Afari and Buchwald, 2003). In comparison, 10% of American adults have a major depressive episode each year, and 17% have had at least one lifetime episode (Kessler et al., 1994). Depressive disorders are characterized by heterogeneity in terms of clinical symptoms, course and treatment response. On the basis of symptom patterns and clinical course, several subtypes of depressive disorders have been defined in the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV) (American Psychological Association, 1994). Some of these subtypes are clearly different from CFS, whereas other subtypes resemble CFS, which might suggest that these disorders and CFS are part of a spectrum of disorders. For example,

- Major depression with a primary mood disturbance (e.g., sadness) can be readily separated from CFS.

- Major depression with the primary symptom of anhedonia (lack of interest) may be less clearly differentiated.
- Chronic minor depressive syndromes (dysthymia) may be more difficult to distinguish.
- Atypical depressive disorders (with primary symptoms of fatigue and anergia) may also be less clearly discernable.

The behavioral clinician should be aware of overlapping features between certain forms of depressive disorders and CFS, and select treatment options based on the types of symptoms present.

**Comorbid Conditions:** Some patients under evaluation for CFS may also have been diagnosed with other medically unexplained illnesses, such as fibromyalgia, Gulf War illness, anxiety disorders, somatoform disorders, irritable bowel syndrome, temporomandibular joint disorder and multiple chemical sensitivity. Some authors have proposed that these illnesses are part of the same continuum as CFS (Wessely and White, 2004). Appropriate therapy and rehabilitation of persons 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 provider is developing a therapeutic plan, since effective treatment must address both CFS and the accompanying disease. Providers 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 are specific treatments. The symptoms of CFS wax and wane in occurrence and severity; however, changes in symptoms or impairment should not be automatically assigned to the CFS diagnosis.

## Course of Illness

To date, there are no reliable predictors of the long-term course of CFS and no treatments or patient characteristics have been associated with full recovery. Most people with CFS report a pattern of relapse and remission and changes in the nature and severity of symptoms (Nisenbaum et al., 2003). The clinical course of illness ranges from substantial recovery to worsening symptoms (Reyes et al., 1997). Many patients experience improved function over time and are able to increase their work and other activities even though they continue to experience symptoms. Clinical research suggests that younger age at onset, shorter duration of illness, milder fatigue and absence of comorbid psychiatric illnesses lead to better prognoses (Afari and Buchwald, 2003; Joyce, Hotopf and Wessely, 1997). However, the timing of diagnosis, duration of illness, and initiation of therapy in relation to outcome of illness have not been studied prospectively (Nisenbaum et al., 2003). These variables may be important in view of

the better prognosis seen for patients who are cared for by their primary care providers versus those subsequently seen in tertiary or specialty care centers (Joyce et al., 1997).

## Evaluating CFS and Developing 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 ways 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. Providers are encouraged to also consider the following suggestions:

- A visual pain diagram 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 (Karper and Stasik, 2003; ACSM, 2000).
- Simplified questionnaires, such as the Subjective Functional Capacity Survey (Lapp, 1993), can help assess functional impairment and track improvement in response to therapy. The treatment plan and patient response to treatment can be evaluated with information from these questionnaires during regular follow-up reviews
- 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 (Bailey, 2003). 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, available at U.S. Centers for Disease Control [Borg, 1998], accessed 2006). How are you feeling?
  - **The day after the session:** Ask the person 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.)

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.

Standardized and validated instruments are also available to assess specific areas of impairment and to evaluate the occurrence and severity of individual symptoms in a quantitative manner. These instruments may be particularly useful to practitioners and clinics specializing in the care of persons with CFS and in documenting disability for third-party providers. CDC recommends use of the Medical Outcomes Survey Short Form-36 (SF-36) (Ware and Sherbourne, 1992), 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. CDC recommends use of the recently validated CDC Symptom Inventory (Wagner et al., 2005) 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 in the general population. It will be freely available from CDC and scoring is straightforward. Finally, the Multidimensional Fatigue Inventory (MFI) (Smets et al., 1995) 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 (Reeves et al., 2005).

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.

## 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. The overall

treatment plan must address these life-altering changes and the patient's emotional reactions to them.

- **Patients:** By definition, CFS "results in substantial reduction in previous levels of occupational, educational, social and personal activities." Patients may experience 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 (Lutgendorf et al., 1995).

Persons with CFS may feel traumatized and stigmatized because family, friends, medical practitioners, employers, coworkers and others do not recognize the incapacitating nature of their illness (Shlaes, Jason and Ferrari, 1999). 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.

Finally, depression is common in persons with CFS. Feelings of worthlessness, inappropriate guilt, recurrent thoughts of death, recurrent suicidal thoughts, having a specific plan for committing suicide and prior suicide attempts define major depressive disorders. Behavioral health professionals in particular should be aware of and address signs of depression as necessary. All professionals who provide treatment and rehabilitation services for CFS patients should understand that inappropriately or inadequately counseled CFS patients could become suicidal.

- **Children and Adolescents:** Adolescents and children may also develop CFS, although it is identified less commonly in persons younger than 18 years than in adults (Jones et al., 2004; Mears et al., 2004). The 1994 definition was designed to identify adults with the syndrome, and these criteria may not be entirely adequate in assessing CFS in younger people. The unique aspects and challenges of chronic illness in youth, including CFS, warrant special mention.
  - Young people may not perceive or 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 lack a sense of "normal" and do 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 (Jones et al., 2004). Consideration of information provided by both parents and children is recommended.
  - 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 may qualify for educational accommodations under the Individuals with Disabilities Education Act or the Rehabilitation Act (United States Department of Education, accessed 2006). Health 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 education strategies should be reviewed regularly because the goal of therapy is return to full participation (academic, development, social, intellectual); as this is achieved, alternative education is not only no longer necessary, but may complicate full development.
- **Family Members and Friends:** Chronic illnesses, such as CFS, affect not only the individual, but her/his family members, caretakers and friends as well. Health care providers should be alert to such family problems. Behavioral providers should identify and address any underlying family problems that contribute to symptoms or result from having a sick child in the family. Identification of these problems is key to instituting appropriate therapy. Family reactions can range from skepticism to overprotection. Family problems may be particularly important in CFS because healthy people find it hard to understand the variability of the 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. Family members should be encouraged to participate in the treatment program.

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, 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 (Jackson, 1999).

- **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 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 having a person with an "invisible" disability in the workplace are not addressed by the legal system.

## Management of CFS

The objectives of an effective CFS management program are first, to improve quality of life by decreasing symptoms and their impact; second, to enhance function; and third, to help the person with CFS set realistic goals and expectations. Often, people with CFS were highly active, productive individuals before they became ill. Helping people adjust their expectations with the limitations imposed by CFS can help reduce negative feelings of stress, anxiety or anger, all of which can exacerbate symptoms. Providers are encouraged to assist people with CFS to understand that hope for improvement is realistic, but immediate and complete restoration of pre-illness status and functioning are not the main goals 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 and other primary care providers, 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 providers who manage any aspect of patient care are encouraged to contact other treating professionals who may be receptive to coordinated care.

Once the allied health care provider has completed an initial history and assessment (as discussed previously), it is important to understand the patient's goals for therapy. Ideally, therapy will focus on those problems that most significantly interfere with the patient's function or quality of life. All CFS management strategies should be individually developed, with each patient's particular abilities, needs and concerns at the forefront, since pre-therapy activity levels and abilities vary greatly among the CFS population. The allied health care provider may need to help patients set realistic goals, such as gradual improvement in quality of life, rather than rapid recovery. The provider needs to help orient patients to what can be achieved with an effective treatment plan; for example, symptom relief, stress reduction and improved coping at first and improved function and quality of life over several weeks to months. It may be helpful to advise patients to reduce other daily activities as they begin a rehabilitation program that includes physical activity. By prioritizing the activity program at the

outset, improvement in stamina and function are more likely to occur over time. If the program is successful, ultimately the person with CFS will be able to do more activities with less risk of relapse.

Considerations for an effective CFS activity management program are listed below.

- **Features of Post-Exertional Malaise:** Post-exertional 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 such that the person with CFS may require bed rest for several days. 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 (Stevens, 2004). Professionals responsible for rehabilitation should carefully consider this aspect of CFS when selecting and implementing interventions and should take seriously 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, as noted earlier.

A few persons with CFS are so severely ill that they are largely bed bound or housebound. They require special attention, including a limited approach to exercise that is focused on maintaining or increasing flexibility, minimizing the impact of deconditioning and developing the ability to accomplish activities of daily living. Assistance with coping skills and a review of behavioral factors are indicated as well.

- **Cognitive Behavioral Therapy (CBT):** The goal of CBT is to change a person's perceptions, beliefs and behaviors that 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 (Deale et al., 2001).

For people with CFS, CBT is designed to promote a healthy balance between activity, rest and leisure (Bleijenberg, Prins and Bazelmans, 2003; Taylor, Friedberg and Jason, 2001). People with CFS generally try to do more than they can capably manage. Specifically, they engage in a "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 (Bleijenberg et al., 2003). The techniques of CBT, including pacing, graded activity and graded exercise and related cognitive interventions, are intended to constructively alter this detrimental cycle.

Some people with CFS are reluctant to engage in CBT or exercise therapy 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 should be explained to the patient that lifestyle and stress can influence physical symptoms and illnesses. Providers can assist patients in understanding the principles of CBT,

including its successful application in treating other medical conditions. However, if a person is actively resistant to CBT or exercise therapy, it should not be forced upon them (Bleijenberg et al., 2003).

- **Activity Pacing:** Activity pacing involves moderating activity to minimize the push-crash cycle and its consequences of more stress, discouragement and frustration (Friedberg and Jason, 1998). 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, cognitive interventions can address patient self-criticisms of laziness, fears of increased disability and discouragement over the loss of pre-illness abilities. Once patients are stabilized, activity is incrementally increased (Bleijenberg et al., 2003).
- **Graded Activity and Graded Exercise:** Graded activity and exercise may be integral parts of CBT or they may be prescribed as stand-alone interventions supervised by rehabilitation specialists. The goals of graded activity are encouraging healthy, balanced activity patterns and promoting feelings of control and self-efficacy. These cognitive variables are important predictors of outcome in CFS patients (Prins et al., 2001; Vercoulen et al., 1996). Controlled trials have shown that graded exercise can be effective in decreasing fatigue and improving functioning (Fulcher and White, 1997; Wallman et al., 2004).

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 (Bailey, 2003).

Activity must be started slowly and at low enough levels so as not to exacerbate fatigue, pain or other symptoms. Activity is always followed by rest; a ratio of 1:3 of activity to rest (i.e., rest period should last three times as long as the activity) is recommended by exercise physiologists who work with CFS patients. 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 1 to 3 minutes of stretching, strength exercises or light aerobic activity (e.g., walking or cycling). These sessions are slowly increased (e.g., 1 to 5 minutes a week) as tolerance develops over 2 to 6 months. These exercises are 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 (Bailey, 2003; U.S. Centers for Disease Control [Borg 1998], accessed 2006).

If patients experience an exacerbation in symptoms, they should return to the most recent manageable level of activity (Bleijenberg et al., 2003). 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 (Lloyd, 2004; Wallman et al., 2004).

Because a major CFS symptom is exacerbation of illness after even minimal physical or mental activity, many patients believe that exercise contributes to the underlying disease process and consequently avoid activity (Lloyd, 2004). 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 because of the high probability that their symptoms will increase with this type of "lock-step" graded exertion. In these cases, practitioners 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 intensity low 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 (Stevens, 2004).

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 2 to 4 repetitions, building to a maximum of 8 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 and thereby avoid post-exertional 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.

- **Pacing/Envelope Theory:** Energy management programs, such as pacing and envelope theory, are variations of CBT. They 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. Although they appear to be similar, the difference between this form of pacing and the type used in association with CBT is that CBT pacing is closely linked with other behavioral techniques that are presumed to increase physical functioning.

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 (Pesek, Jason and Taylor, 2000). 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 post-exertional exacerbation of symptoms.

These methods tend to be supported by patients, even though there has been little formal research into their efficacy (CFS/ME Working Group, 2002). 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 to CFS patients (Lloyd, 2004; Wallman et al., 2004).

- **Other Health Issues:** For many people with CFS, there are a number of health consequences of having CFS that can be addressed and often resolved with standard therapies 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 in some cases combined medication and psychotherapy 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 (Taylor and Kielhofner,



2003; Batiste and Loy, 2004). 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.

- **Coping skills:** Some people with CFS may have difficulty developing effective coping skills. These problems can be addressed by a competent therapist using problem-solving techniques and standard psychotherapeutic and counseling methods.
- **Family issues:** CFS impacts the entire family structure. In many cases the therapist will want to involve other family members to educate them and to resolve issues resulting from, or related to, CFS. This approach is particularly pertinent in the case of a child or adolescent with CFS.
- **Empathy:** People with CFS often feel misunderstood and isolated. They need reassurance that the therapist does not attribute all their symptoms to psychological problems, accepts their CFS diagnosis and the reality of their suffering and provides an environment where they may safely discuss issues regarding the impact of their illness.

**Symptom-Based Therapies:** Because many CFS symptoms have behavioral and functional consequences, behavioral health and rehabilitation specialists may be likely to observe them before other health care professionals. In these cases, the specialist may recommend that the person with CFS consult their primary care provider. CFS treatment is aimed at alleviating symptoms, and standard rehabilitative therapies for symptoms such as pain, cognitive problems and poor stamina are generally effective in CFS. The main difference is that therapy will require a slower pace to reduce the possibility of exacerbating symptoms.

- **Sleep:** Unrefreshing sleep is a major CFS symptom and addressing this problem is an important management consideration. Primary sleep abnormalities may present as CFS and such problems require evaluation by a sleep specialist. Sleep disturbances may also be a side effect of certain medications, including those used to treat psychiatric disorders. It is also important to note that many persons with CFS have unusual reactions to

medications, particularly those with sedating effects; it is generally necessary to start dosages at  $\frac{1}{4}$  to  $\frac{1}{2}$  the usual prescribed dose and adjust to safe, therapeutic levels. Behavioral health specialists can help people with CFS adopt better sleep habits, in accordance with standard sleep hygiene techniques. These techniques are often incorporated in comprehensive CBT programs, 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, and schedule regular sleep and wake times. Rehabilitation clinicians should remind patients that exercise should take place at least 4 hours before going to bed. A sleep specialist should evaluate patients whose sleep remains non-restorative following the above interventions.

- **Pain:** Muscle pain, joint pain and headaches are also major CFS symptoms, yet not everyone with CFS reports pain as a significant symptom. If pain is a problem voiced by persons with CFS, pain specialists, rheumatologists and rehabilitation professionals may be helpful. Pain following physical activity does not always mean an exacerbation of CFS symptoms. As patients improve in an exercise program, pain may be a normal consequence of increasing activity. However, resumption of fatigue with increasing pain does suggest an excessive level of activity.
- **Other symptoms or conditions:** People with CFS are advised to report new or worsening symptoms to their primary medical care provider. Because CFS symptoms fluctuate, many people attribute new symptoms to CFS when they may actually be caused by other illnesses. Failure to properly evaluate new symptoms may have devastating consequences if other diagnoses are not recognized or treated.

## Disability

By definition, all patients with CFS are functionally impaired. Studies have shown a marked shift from premorbid employment status, when most worked full time, to a substantially decreased number being able to maintain full-time employment after becoming ill.

The application process for disability benefits is often protracted and frustrating for both patients and providers. When a patient applies for disability benefits, treating-professionals are a major source of pertinent information.

## Conclusion

CFS is a complex condition of considerable public health importance. CDC studies document that it affects up to 900,000 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 above, at least a quarter 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 (Reynolds et al., 2004). 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.

Health care providers 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 provider.

CFS is a complex illness with many symptoms that are common to other conditions. Diagnosis and management of CFS can be a challenge, but it is not impossible. Rigorous research is being conducted into its causes and treatment, and federal government agencies offer support for research and education of health care providers and the general public. These efforts provide hope for people afflicted with this illness and professionals who care for them.

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