

## CFS TOOLKIT FOR HEALTH CARE PROFESSIONALS

### WHAT'S IN THIS TOOLKIT?

Chronic fatigue syndrome, or CFS, is a debilitating and complex illness that can be challenging to diagnose and treat. These challenges often leave both patients and health care professionals locked in a cycle of frustration.

This CFS toolkit is designed to help break this cycle. It provides a quick and easy-to-use resource for clinical care. In less than 30 minutes, you can review the best practices related to diagnosing and managing CFS. You can also learn about other credible resources, ongoing CFS research and continuing education opportunities.

Whether you are a physician, nurse practitioner, physician assistant or other health care professional, you *can* help patients with CFS. You can assist patients in managing symptoms, improving function, conserving energy and monitoring activity levels. While there is still no cure for CFS, there *are* treatment options that help patients improve their quality of life and increase activities of daily living.

### WHAT IS CFS?

Chronic fatigue syndrome is an illness characterized by profound, debilitating fatigue lasting at least six months 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. These symptoms include problems with memory and concentration, unrefreshing sleep, muscle and joint pain, headaches, tender cervical or axillary lymph nodes, recurrent sore throat and an increase in fatigue and in patient-specific symptoms persisting longer than 24 hours following mental or physical exertion.

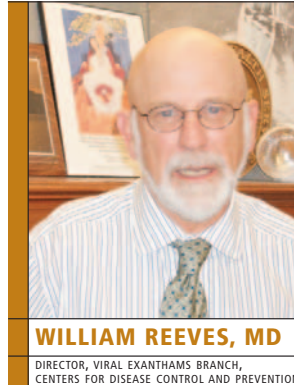
The clinical course and symptom severity of CFS varies considerably among the patient population. There is frequently an intermittent pattern of relapse and remission. The illness is marked by a dramatic decline in activity level and stamina. People with CFS perform at a significantly lower level of activity than they were capable of prior to the onset of the illness.

As yet, there are no diagnostic tests or laboratory markers for CFS, and its pathophysiology is unknown.

### WHY IS CFS A PUBLIC HEALTH CONCERN?

There are several reasons health professionals should be knowledgeable about CFS:

- ◆ **More than one million Americans have CFS.** This illness strikes more Americans than multiple sclerosis, lupus, lung cancer or ovarian cancer.



"Chronic fatigue syndrome is not rare. In fact, CDC research indicates that more than one million Americans have CFS, yet less than 20% have been diagnosed. This is a major public health concern."

- ◆ **Less than 20% of Americans with CFS have been diagnosed.** The low rate of diagnosis supports a need for increased CFS awareness among individuals experiencing the symptoms of the illness and among providers throughout the health care system.
- ◆ **CFS can be debilitating.** By definition, all CFS patients are functionally impaired. While symptom severity varies from patient to patient, 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 has a severe economic impact.** The annual economic impact of chronic fatigue syndrome in the United States is estimated to be \$9.1 billion in lost productivity, not including medical costs or disability benefits. The average family affected by CFS loses \$20,000 a year in wages and earnings.

### WHO IS AT RISK FOR CFS?

Researchers continue to explore possible causes, risk factors and triggering factors for CFS. Many questions remain, but there are some characteristics that may help health care practitioners identify patients who are most at risk for CFS. 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

## CFS TOOLKIT OVERVIEW

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.

### OVERCOMING OBSTACLES TO CLINICAL CARE

In several recent research studies funded by the CDC, common barriers to diagnosing and treating CFS were identified among primary care practitioners, including family practice physicians, internists, nurse practitioners and physician assistants. Overcoming these obstacles can increase diagnostic rates and improve therapeutic outcomes for CFS patients. The most common obstacles identified were:

- ◆ **Uncertainty about whether CFS is real.** After more than 3,000 research studies, there is now abundant scientific evidence that CFS is a real physiological illness. It is not a form of depression or hypochondriasis. A number of biologic abnormalities have been identified in people with CFS, but how they contribute to the illness is still unclear.
- ◆ **Uncertainty about how to diagnose CFS.** Although there is no laboratory test or marker to identify CFS, there is an international case definition for chronic fatigue syndrome that provides a reliable diagnostic algorithm.

◆ **Uncertainty or hesitancy about making a diagnosis that may contribute to the illness.** Validating a patient's illness experience may have therapeutic value and reduce the cycle of frustration between patients and their health care team. There is also evidence to suggest that the longer a person is ill before a diagnosis, the more complicated the course of the illness appears to be, making early detection and treatment of CFS of utmost importance.

◆ **Uncertainty about how to treat CFS.** Although managing CFS can be challenging, there are a number of therapeutic strategies that health professionals can use to tailor a multidimensional treatment program.

### WHAT IS THE CLINICAL COURSE OF CFS?

CFS often follows a random course, alternating between periods of illness and relative well-being. The nature of the symptom complex often changes over time as well.

The percentage of patients who recover is unknown. Some patients recover completely with time. Others improve to the point that they can resume work and other activities, but continue to experience periodic CFS symptoms. Some patients grow progressively worse. Studies conducted by the CDC have found that 40-60% of people with CFS report partial or total recovery, but more research on the long-term course of the illness is needed to validate these findings.

There is some evidence to indicate that the sooner a patient is treated, the better the chance of improvement. This means delays in diagnosis and treatment could adversely affect therapeutic outcomes.



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## CFS TOOLKIT FOR HEALTH CARE PROFESSIONALS

### DIAGNOSTIC CHALLENGES

Diagnosing chronic fatigue syndrome (CFS) can be challenging for health care professionals. A number of factors add to the complexity of making a CFS diagnosis: 1) there is no diagnostic laboratory test or biomarker for CFS, 2) fatigue and other symptoms of CFS are common to many illnesses, 3) many people with CFS do not look sick in spite of their profound disability, 4) symptoms vary from person to person in type, number and severity and 5) symptoms may vary in an individual patient over time.

These factors have contributed to an alarmingly low diagnosis rate. Of the more than one million Americans who have strictly defined CFS, more than 80% have not been diagnosed yet.

### DIAGNOSING CFS

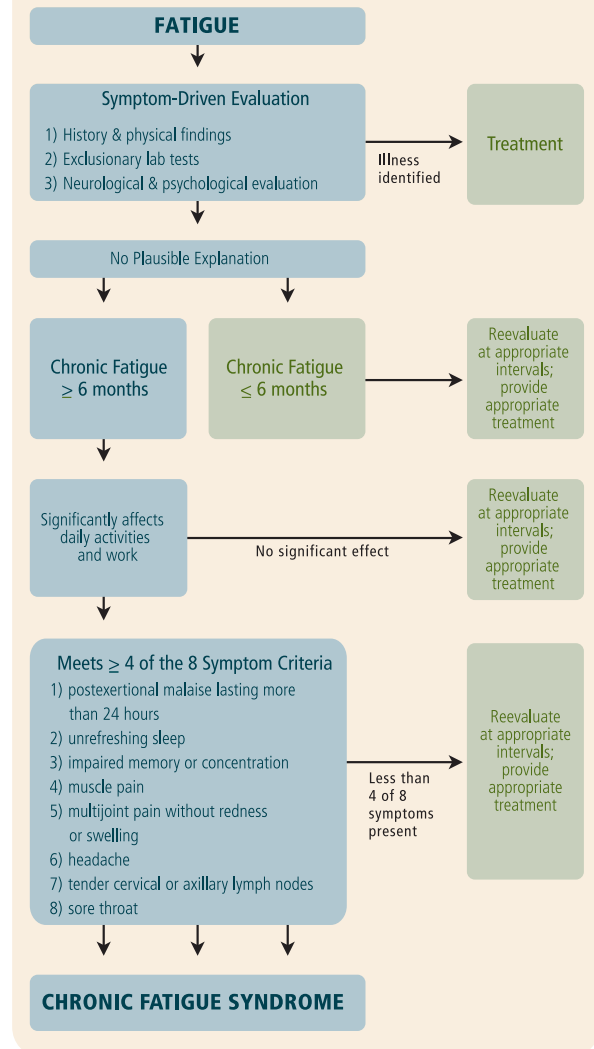
To be diagnosed with CFS, patients must experience significant reduction in their previous ability to perform one or more aspects of daily life (work, household, recreation or school). And by definition, all people suffering from CFS experience severe, all-encompassing mental and physical fatigue that is not relieved by rest and that has lasted longer than six months. The fatigue is accompanied by characteristic symptoms that may be more bothersome to the patients than the fatigue itself.

Clinicians should consider a diagnosis of CFS if these two criteria are met:

1. Unexplained, persistent fatigue that is not due to ongoing exertion, is not substantially relieved by rest, is of new onset (not lifelong) and results in a significant reduction in previous levels of activity.
2. Four or more of the following symptoms are present for six months or more:

- ◆ Impaired memory or concentration
- ◆ Postexertional malaise (extreme, prolonged exhaustion and exacerbation of symptoms following physical or mental exertion)
- ◆ Unrefreshing sleep
- ◆ Muscle pain
- ◆ Multijoint pain without swelling or redness
- ◆ Headaches of a new type or severity
- ◆ Sore throat that is frequent or recurring
- ◆ Tender cervical or axillary lymph nodes

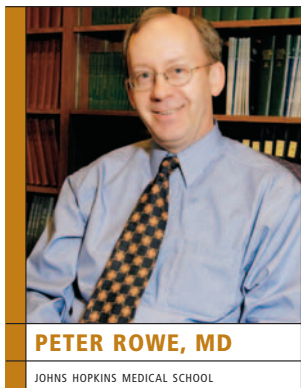
### CFS EVALUATION AND DIAGNOSIS MODEL



### DIAGNOSTIC MODEL

The 1994 International Case Definition forms the basis for a reliable diagnostic algorithm for CFS, particularly in adults. Clinicians assessing adolescents for pediatric CFS should exercise judgment based on the course of the illness and the patient's medical history.

## CFS TOOLKIT DIAGNOSING CFS



"Because there's no diagnostic test or biologic marker for CFS, it's a diagnosis of exclusion. But CFS can be diagnosed in a primary care setting. Referring patients just to confirm a CFS diagnosis is costly and usually unnecessary."

### CLINICAL EVALUATION

When the CFS criteria are met, health professionals need to exclude other illnesses before a diagnosis can be confirmed. Because there is no diagnostic lab test for CFS, it is a diagnosis of exclusion.

Clinical evaluation of patients with a fatiguing illness requires:

- ◆ A detailed patient history, including a review of medications that could cause fatigue
- ◆ A thorough physical examination
- ◆ A mental status screening
- ◆ A minimum battery of laboratory screening tests.

Recommended tests include:

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

Further tests or referral to specialists may be indicated to confirm or exclude a diagnosis that better explains the fatigue state or to follow up on results of the initial screening tests.

There are several questionnaires that can assist with the identification and monitoring of CFS patients. These include the MOS SF-36, Multidimensional Fatigue Inventory (MFI), the McGill Pain Score, the Sleep Answer Questionnaire and the CDC Symptom Inventory.

### COMORBID CONDITIONS

It is not uncommon for CFS patients to present with symptoms of other illnesses, and some patients actually receive diagnoses for multiple conditions. Because many of these conditions lack a diagnostic test or biomarker and share symptoms such as fatigue and pain with CFS, unraveling which illnesses are present can be difficult.

Comorbid conditions that clinicians should be alert for include irritable bowel syndrome, multiple chemical sensitivity, Gulf War syndrome, temporomandibular joint disorder and interstitial cystitis. Fibromyalgia appears to be the most common overlapping condition with CFS. Research suggests that between 35-70% of CFS patients also have fibromyalgia, so it is helpful for clinicians treating CFS patients to be familiar with diagnostic and treatment practices for both illnesses.

### EXCLUSIONARY CONDITIONS

Chronic fatigue syndrome can resemble many other disorders, including mononucleosis, Lyme disease, lupus, multiple sclerosis, primary sleep disorders like narcolepsy or sleep apnea, hypothyroidism, severe obesity and major depressive disorders. All these conditions must be considered and, if present, receive appropriate treatment. Medications can also cause side effects that mimic the symptoms of CFS.



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## CFS TOOLKIT FOR HEALTH CARE PROFESSIONALS

### 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. That is why a discussion of CFS management guidelines begins with supportive care.

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 doctor-patient relationship.

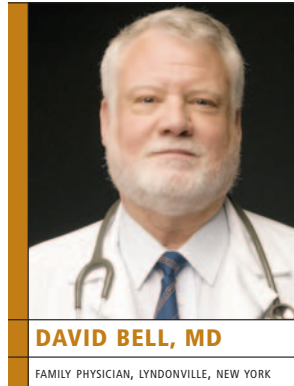
### ADDRESSING THE PHYSICAL AND EMOTIONAL TOLL

Like other 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 challenges. Common difficulties include problems coping with the variable and unpredictable symptoms; a decrease in stamina that interferes with activities of daily living; memory and concentration problems that seriously impact work or school performance; uncertain prognosis; loss of independence, livelihood and economic security; alterations in relationships with family and friends; and feelings of guilt, isolation and abandonment. Patients may also worry about bearing and raising children and the potential impact of decreased sexual activity on intimate relationships.

The overall treatment plan should acknowledge these challenges and the patient's emotional reaction to them. Educating patients about the link between stress and symptom exacerbation is key to establishing effective coping strategies and a positive approach to adapting to the illness.

### THE BASICS OF SUPPORTIVE CARE

There are several components of supportive care that should be considered when creating an individualized care program for your CFS patient.



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"Chronic fatigue syndrome can be challenging to treat. But helping patients develop effective coping strategies and treating pain, sleep problems and other prominent symptoms can make a huge difference in a patient's quality of life."

**1. Validating the illness experience.** Because CFS is an "invisible illness," patients often do not look sick. Public misconceptions about CFS being "all in your head" contribute to a social context that leaves many patients feeling misunderstood and isolated as they routinely face skepticism from others. Having to confront negative responses to their illness is a source of considerable anxiety for many patients.

Be particularly conscious of your attitude, and provide a supportive environment where patients can safely discuss their illness. Treating patients with respect and validating their illness may be the single-most important therapy you can provide.

**2. Professional counseling.** Referral to a mental health professional may be indicated to help build effective coping skills. A supportive counselor can help patients cope with the prospects of long-term illness, as well as the anxiety, depression, grief, anger and guilt that frequently accompany any chronic illness. These issues can be addressed by a competent therapist using problem-solving techniques and standard psychotherapy and counseling methods. In some cases combined medication and psychotherapy may be required.

Health care providers should be alert to family problems and institute appropriate care management. Consults with behavioral health providers may be necessary. You may want to encourage all family members to participate in behavioral therapy to address changes in family dynamics related to living with CFS.

**3. Alternative therapies.** Deep breathing and muscle relaxation techniques, massage and healing touch, and movement therapies like stretching, yoga and tai chi can be beneficial for some CFS patients in reducing anxiety and promoting a sense of well-being.

Patients should be encouraged to discuss all potential alternative therapies with a health professional since many CFS treatments that are heavily promoted on the Internet are unproven at best, and potentially dangerous at worst.

## CFS TOOLKIT MANAGING SUPPORTIVE CARE

**4. Cognitive behavioral therapy (CBT).** The goal of CBT is to help patients cope with their illness and change perceptions and behaviors that can contribute to symptom expression. While CBT is frequently prescribed as a coping strategy, it can also improve fatigue and activity levels. Optimally, CBT can help your patients better adapt to the impact of CFS and improve their quality of life.

Some patients are resistant to this therapy because they mistakenly believe health practitioners who prescribe CBT believe CFS is purely a psychological illness. Educating patients about the role CBT can play in helping them learn to manage activity levels, stress and symptoms may help overcome this reluctance.

See the fact sheet on CBT in this toolkit for more information.

**5. Support groups.** Many people with CFS find it therapeutic to meet with other people who have this illness. A good CFS support group should provide a warm and caring environment where patients can share their experiences and tips for living

with a chronic illness. Support groups can help fulfill their need for information, empathy and a sense of community as patients learn to cope and adapt to life with a chronic illness. Encourage patients to seek out support groups with a positive focus instead of “gripe sessions” that may add to their stress.

### DISABILITY

By definition, all people with CFS are impaired. While many patients are able to adapt to their functional limitations, others suffer occupational disability. Depending on the level of impairment, CFS patients can lose their jobs, economic security and homes. Helping severely impaired patients accept and cope with the fact that they are no longer able to work and must rely on disability benefits can have therapeutic value.

Also of value in reducing patient anxiety is being a willing participant in the disability process. The health care professional is a major source of documentation in this process. Keeping good clinical notes and using simple assessment tools to track health status are important to the benefits process.



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## CFS TOOLKIT FOR HEALTH CARE PROFESSIONALS

### SYMPTOMATIC TREATMENT

People with CFS complain of different primary symptoms. Symptom severity can also vary considerably. Clinicians should query patients about which symptoms are most disruptive or disabling and tailor the management plan accordingly.

Primary symptoms may include sleep problems, muscle and joint pain, cognitive dysfunction, fatigue, headaches, sore throat and postexertional malaise. Gastrointestinal complaints, orthostatic instability, depression and allergies are also seen in many patients. Aggressive symptom management for these and other disruptive symptoms is indicated.

### PHARMACOLOGIC THERAPY

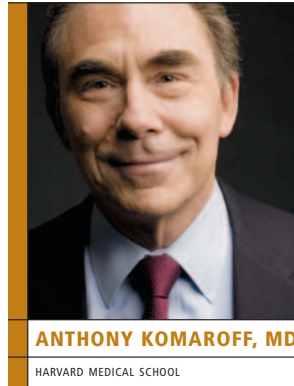
There are many over-the-counter and prescription drug therapies that can be used to treat CFS symptoms. Health care professionals can:

- ◆ Use as few drugs as possible. For instance, tricyclic antidepressants help with both sleep and pain.
- ◆ Reduce the initial dose because many CFS patients are very sensitive to medications, particularly agents acting on the central nervous system. Try prescribing a fraction of the usual recommended dose to start and gradually increase as necessary and as tolerated.
- ◆ Monitor drug side effects like weight gain, secondary fatigue, daytime sedation, cognitive problems and sleep disturbance.
- ◆ Understand that you may need to systematically try various interventions. A drug that is beneficial for one CFS patient may be ineffective for another.

### NUTRITIONAL AND HERBAL SUPPLEMENTS

It is not uncommon for people with CFS to take numerous nutritional supplements and vitamins as they desperately seek symptom relief.

- ◆ Guide patients in selecting supplements. While there have been few clinical trials to support the use of particular supplements, some may be efficacious. Studies have investigated or reported the use of supplements, including oral NADH, high doses of vitamin B12, essential fatty acids, vitamin C and coenzyme Q10. These studies show inconsistent results, but symptom improvement was reported in some subjects.
- ◆ Question patients about supplement use and OTC products to determine safety, efficacy and possible negative interactions with prescribed medications.



"In the past, there have been questions about whether CFS is a real illness. There is now a preponderance of scientific evidence that CFS is a real biological illness. It's not a form of depression or hypochondria."

- ◆ Advise your patients to avoid herbal remedies like comfrey, ephedra, kava, germander, chaparral, bitter orange, licorice root, yohimbe and any other supplements that are potentially dangerous.

### ALTERNATIVE THERAPIES

Alternative therapies are often explored by CFS patients, particularly when traditional drug treatments do not provide enough symptom relief.

- ◆ Encourage patients to discuss such options with you to make sure they are safe and effective.
- ◆ Remain open-minded about alternative therapies. For example, many clinicians report that hydrotherapy simultaneously provides exercise, improves balance, treats orthostatic instability and reduces CFS pain.
- ◆ Consider referring patients to an acupuncturist. This treatment is often prescribed for chronic headaches, pain and decreased energy. Finding a certified practitioner who is knowledgeable about CFS is best.
- ◆ Consider other alternative therapies. Gentle massage, meditation, deep breathing, relaxation therapy and biofeedback have helped some patients. Movement therapies like stretching, physical therapy, yoga and tai chi may be effective for CFS patients who can tolerate more activity.

### TREATING SPECIFIC SYMPTOMS

- ◆ Recognize that unrefreshing sleep is a case-defining symptom, and the vast majority of CFS patients complain of some form of sleep-related symptoms. Sleep deprivation or disruption may cause or exacerbate other symptoms such as fatigue, impaired cognition, headaches and joint pain, so treating sleep problems should occur early in the treatment program.

## CFS TOOLKIT MANAGING SYMPTOMS

- ◆ Advise patients to practice standard sleep hygiene techniques. Light exercise and stretching at least four hours before bedtime can also improve sleep.
- ◆ Set up a consult with a sleep specialist or schedule a sleep study for a CFS patient if patients identify problems with their sleep.
- ◆ Random use of sleep medications may prolong identification of a sleep disorder or induce additional sleep problems. Sleep medication should be based on the patient's responses to a thorough sleep history if a sleep consult is not readily available.
- ◆ Consider pharmaceuticals if sleep hygiene is not successful. Initial medications to consider are simple antihistamines or over-the-counter sleep products. If this is not beneficial, then start with a prescription sleep medicine in the smallest possible dose. Both sleep-initiating and sleep-sustaining drugs may be indicated for some CFS patients.
- ◆ Pain therapy should be limited to simple analgesics like acetaminophen, aspirin or NSAIDS. Narcotics should only be considered by a pain specialist after careful identification of patient-specific pain pathways and testing for efficacy of specific agents.
- ◆ Include nonpharmacological modalities and alternative therapies in your pain management program.
- ◆ Treat depression when it is present. Depression is a common comorbid illness in patients with CFS, with as many as half of patients developing secondary depression as a result of the illness. Careful evaluation of the patient is required in order to identify an exacerbation of either illness before therapy can be undertaken. Treating depression can reduce anxiety and stress, and assist in relief of symptoms.
- ◆ Use caution in prescribing antidepressant drugs. Antidepressants of various classes may act on other CFS symptoms or cause side effects.
- ◆ There are brief psychiatric screening tools available that can be administered and scored in the primary care setting. Refer patients to a mental health professional if indicated.
- ◆ Be alert for symptoms of orthostatic instability, in particular frequent dizziness and light-headedness. Patients should be referred for evaluation by a cardiologist or a neurologist to confirm orthostatic problems before initiating treatment.
- ◆ Suggest coping and adaptive techniques for cognitive difficulties like memory and concentration problems. Memory aids, such as organizers, schedulers and written resource manuals, are usually recommended. Stimulating the mind with puzzles, word games, card games and other activities can also be helpful.
- ◆ Refer CFS patients with disabling cognitive problems to behavioral health professionals for specific techniques to help them function better.
- ◆ Prescribe stimulants only for diagnosed conditions. Mild stimulants may be helpful for some CFS patients, but stronger stimulants can precipitate the "push-crash cycle" and cause relapse (see *Managing Activity*).



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## CFS TOOLKIT FOR HEALTH CARE PROFESSIONALS

### A DIFFERENT DEFINITION OF EXERCISE

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.

### AVOIDING TWO EXTREMES

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.

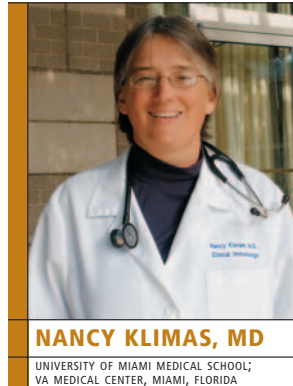
Some people with CFS inappropriately avoid all activity because personal experience has demonstrated a link between exertion and symptom severity. An even greater number of people engage in an endless “push-crash” cycle in which they do too much, crash, rest, start to feel a little better and do too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

It is important that emphasis be placed on avoiding these two extremes and balancing activity. Appropriate rest is a vital 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.

### THE IDEAL CLINICAL TEAM

The ideal clinical team is comprised of a caring and listening provider and an informed but receptive patient. Working with other health professionals like physical therapists, rehabilitation specialists, exercise therapists or occupational therapists can be especially beneficial when such allied professionals are available.

Such a multidisciplinary health care team can tailor an exercise and activity program that meets the needs of the individual patient. The team can assist in identifying goals and setting realistic expectations. Including the CFS patient as a full partner in developing this highly individualized activity plan is important so patients can eventually learn to manage the plan on their own.



“Helping CFS patients redefine exercise in a way that paces activity and avoids postexertional malaise is critical. Exercise won’t cure CFS, but it can help avoid deconditioning and ameliorate symptoms.”

Although a therapeutic team approach is ideal, primary care practitioners who “team up” with their patients can provide very effective care.

### 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.

### GRADED ACTIVITY AND EXERCISE

A principal element of graded activity is to start slowly and increase slowly, gradually increasing both the level of activity and the duration.

- ◆ Teach CFS patients that 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.

## CFS TOOLKIT MANAGING ACTIVITY

- ◆ Advise deconditioned patients to limit themselves 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.

### ENERGY MANAGEMENT PROGRAMS

Two energy management programs—pacing and envelope theory—may be useful for CFS patients. These are often part of cognitive behavioral therapy (CBT), but they can be prescribed as stand-alone interventions.

Activity pacing involves moderating activity to minimize the push-crash cycle. Patients are advised to do specific activities, such as household tasks, in small, manageable chunks with rest breaks, rather than in a single energy-depleting effort. Activity should be spread evenly throughout the day, and it should not exacerbate fatigue or other symptoms. Once patients are stabilized, activity is incrementally increased.

Envelope theory instructs patients to view their available energy as if 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. As time passes, patients learn how much energy they can expend without experiencing the characteristic postexertional malaise.

### STRENGTH AND CONDITIONING

A strengthening and conditioning program can reduce pain, improve strength and flexibility, and enhance stamina and function in CFS patients.

- ◆ Encourage patients to start with simple stretching and strengthening exercise, using only body weight for resistance. Gradually add wall push-ups, modified chair dips and toe raises to the routine. Increase repetitions gradually. Patients can begin with a set of 2-4 repetitions and build to a maximum of 8.
- ◆ Add resistance exercise as strength improves. Exercise bands or light weights are both good options.
- ◆ Add a focus on strengthening core abdominal muscles to relieve back pain and improve overall circulation.
- ◆ Advise patients who do not tolerate an upright position to try swimming or a recumbent bicycle.

### SEVERELY ILL PATIENTS

A subset of people with CFS are so severely ill that they are largely housebound or bedbound. They require special attention, including a modified approach to exercise. Hand stretches and picking up and grasping objects may be all that can be managed at first. Gradually increasing activity to the point patients can handle essential activities of daily living—getting up, personal hygiene and dressing—is the next step.

Focusing on improving flexibility and minimizing the impact of deconditioning so patients can increase function enough to manage basic activities is the goal with severely ill patients.



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## CFS TOOLKIT FOR HEALTH CARE PROFESSIONALS

### CFS RESEARCH ON TREATMENTS

Although chronic fatigue syndrome has been the subject of more than 3,000 research studies, most of those have focused on epidemiology and etiology. Only a small body of research has been conducted on the clinical aspects of CFS, including both pharmacologic and nonpharmacologic treatment interventions.

Of the CFS treatments studied to date, two have demonstrated the most promise thus far. The first is activity management/graded exercise, which is covered in another sheet in this toolkit. The second is cognitive behavioral therapy, or CBT, which has been shown to be effective in small, short-term trials. Studies suggest CBT not only helps some CFS patients cope with the impact of a chronic illness, it can be useful in managing the illness. CBT may help patients develop constructive coping strategies, better manage symptoms, improve their level of function and enhance their ability to perform activities of daily life.

### USEFUL FACTS ABOUT CBT AND CFS

Cognitive behavioral therapy is an individualized form of therapy that is based on each individual's illness experience and the impact it has on the person's life. Working with a CBT therapist, CFS patients can examine beliefs, concerns and coping behaviors and modify these as necessary to manage the illness more effectively.

- ◆ The short-term studies of CBT in CFS show improvement in function and symptom management. Some studies also show limited effect on pain and fatigue.
- ◆ 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 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 stress can play in exacerbating the symptoms of CFS is essential. CBT helps patients 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



*"There is now substantial evidence to indicate that CFS has a biologic basis. It is complex and heterogeneous. By combining genetics and gene activity with clinical and epidemiologic data into a molecular profile, we should be able to customize intervention and control CFS."*

accustomed to "boom or bust" cycles in which they engage in a great deal of activity when feeling well and able, then "crash" with exhaustion, may need to curtail activity and more evenly pace exertion from day to day. (See *Managing Activity* in this toolkit for more information.)

- ◆ Formal 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 who can successfully guide CBT. Nurses, physical therapists and occupational therapists are examples of multidisciplinary providers 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.

### MANAGING PATIENT RESPONSES TO CBT

For CBT to be effective, the patient must believe in the potential benefits of this therapy. Public misconceptions about CFS being "all in your head" may cause some patients to resist CBT. They may think health care professionals who prescribe this therapy believe CFS is purely a psychological illness. Assuring patients that you are aware that research indicates that there is an organic, biologic basis for chronic fatigue syndrome and educating them about the role CBT plays in other illnesses can help overcome this reluctance. When patients realize that CBT is used as an adjunct therapy for cardiovascular disease, diabetes, cancer, orthopedic injuries and other medical conditions, and that CBT may help CFS symptoms, they are more likely to be receptive to this therapy.

- ◆ 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.

## CFS TOOLKIT COGNITIVE BEHAVIORAL 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. 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. Health care professionals can encourage use of this mode of therapy when appropriate and assist the patient in locating accurate information on this treatment method, as well as referrals to skilled professionals.
- ◆ 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.

### FOR MORE INFORMATION

Experienced CBT therapists familiar with CFS are still not uniformly available across the United States. The Association for the Advancement of Behavior Therapy (212-647-1890, [www.aabt.org](http://www.aabt.org)) or the National Association of Cognitive Behavioral Therapists (800-853-1135, [www.nacbt.org](http://www.nacbt.org)) may be able to assist in finding a trained provider in your area. Contacting local mental health professional groups, physical and occupational therapists or health care organizations may be helpful as well.

