

# THE CFS RESEARCH REVIEW

Providing up-to-date information on research, diagnosis and treatment of CFS for medical professionals

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## News & Information

### Drug Therapies for CFS

Many physicians and researchers are concerned that there has been a significant lack of new drug therapies for the treatment of CFS and FM in the past few years. According to Charles Lapp, M.D., who treats a number of patients with CFS and FM at his Hunter-Hopkins Center in Charlotte, North Carolina, the picture may be getting brighter. He says new drugs that show promise for the treatment of these illnesses are being studied, and "for the first time we are seeing drugs introduced specifically for CFS and/or FM."

Eli Lilly has introduced its first NSRI (norepinephrine-serotonin reuptake inhibitor), duloxetine (Cymbalta). Because serotonin is usually low in CFS/FM patients, often causing sleep problems, irritability and depression, NSRIs may be a valuable pharmacologic treatment for these patients.

In a study of FM patients, duloxetine reduced pain in 70 percent of the trial subjects, and about 30 percent reported a reduction in pain of at least 50 percent. The drug also improved fatigue and depression.

Cypress Bioscience has also licensed an NSRI, Milnacipran, that is performing similarly to duloxetine in trials. The company is starting its Phase III studies of the drug, which, if approved, will be the first drug to be introduced in the United States specifi-

cally for the treatment of fibromyalgia.

Ampligen is one drug on the horizon that has potential for treating CFS. Ampligen is an experimental, double-stranded RNA drug that may potentially act as an immunomodulator and antiviral. Based on *in vitro* studies, Ampligen is believed to stimulate the immune system as well as inhibit the viral activity directly.

Hemispherx Biopharma, Inc., the manufacturer of Ampligen, announced the completion of the randomized and placebo-controlled stage of its Phase III clinical trial on January 30. The company expects to report clinical data from the study this summer. Look for the data in the *CFIDSLink* as soon as it is released. You can subscribe to this free monthly e-newsletter by calling the CFIDS Association of America at 704-365-2343 or visiting [www.cfids.org](http://www.cfids.org).

### Reader Survey

The *CFS Research Review* was introduced four years ago, and we think it's time to survey our readers to determine how useful it is in its current form, discover what kinds of articles you prefer and hear suggestions for improving this resource on CFS.

Please help us make this publication as effective as possible by filling out the survey on pages 13-14 and mailing it back to us, or faxing it. Your feedback will be very valuable!

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\*Chronic fatigue syndrome  
(CFS) is also known as chronic  
fatigue and immune dysfunction  
syndrome (CFIDS) or myalgic  
encephalomyelitis (ME). For a case  
definition of the illness, see page 16.

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### Cognitive performance impaired in CFS

Attention, information processing speed and motor speed are impaired in CFS patients, according to an NIH-funded study of 141 CFS patients and 76 healthy controls in the March issue of the *Journal of the International Neuropsychological Society*.

On a battery of 18 neuropsychological tests, the CFS group was more likely to perform one standard deviation below the reference mean on nine tests and two standard deviations below the mean on four tests. Memory and executive functioning did not appear to be greatly affected, and no correlation was found between cognitive deficiencies and depression.

The greatest problems seemed to occur on tests requiring motor activity, such as the Digit Symbol and the Grooved Pegboard tests. Prior research by this group showed that CFS patients do poorly on auditory processing tasks. The authors believe that these studies provide evidence that complex information processing is impaired in CFS.

Although CFS patients frequently complain of memory problems, the researchers did not find strong evidence of this on standardized testing. They speculated that the reported memory problems may actually result from the information processing problems, in that patients are



unable to properly store memory and, therefore, are unable to retrieve it.

Because cognitive problems have been previously linked to functional disability in CFS, the investigators suggest that further research should specifically examine the role of neuropsychological dysfunction in predicting physical and functional decline and in maintaining disability.

*Busichio K, Tiersky LA, Deluca J, Natelson BH. Neuropsychological deficits in patients with chronic fatigue syndrome. J Int Neuropsychol Soc. 2004;10(2):278-85.*

### Homeopathy provides modest improvement

A triple-blinded, placebo-controlled study of homeopathy shows that CFS patients experienced modest improvements in general fatigue and physical limitations after six months of treatment. Overall improvement was seen more often in the treatment group as well. The study was published in the February issue of the *Journal of Psychosomatic Research*.

Of 103 CFS subjects enrolled in the study, data on 86 were complete and available for postintervention analysis. The patients, the homeopaths and the data analyst were blinded as to which subjects received homeopathic remedies and which received the placebo. Remedies and placebos were dispensed by a homeopathic pharmacist in a distant city to maintain blinding. Testing showed that neither the patients nor the homeopaths accurately predicted patients' status.

No significant improvements were seen on the Multidimensional Fatigue Inventory (MFI) tests of physical fatigue, mental fatigue, reduced activity or reduced motivation. The treatment group experienced modest gains on the MFI general fatigue subscale and the Functional Limitations Profile (FLP). More people in the treatment group showed clinical improvement on all the study's primary outcomes.

The investigators urge caution in interpreting results, as the degree of improvement was not strong enough to be thoroughly convincing. However, they state, "homeopathic consultations may for certain patients be a useful addition to clinicians' resources for managing patients with CFS."

*Weatherley-Jones E, Nicholl JP, Thomas KJ,*

Parry GJ, McKendrick MW, Green ST, Stanley PJ, Lynch SP. A randomized, controlled, triple-blind trial of the efficacy of homeopathic treatment for chronic fatigue syndrome. *J Psychosom Res.* 2004;56(2):189-197.

### **Immune activation found in CFS**

Subjects with CFS are significantly more likely to have immune activation compared to controls, according to a study published in the February issue of *Clinical & Experimental Immunology*. Researchers found that CFS subjects' immune status was biased toward a Th2 response, a finding that was previously reported by two research groups, but has remained controversial.

The current study enrolled 35 CFS patients and 28 healthy controls. The investigators found no correlation between immune status and illness severity, allergy or antinuclear antibodies. (Allergy and autoimmune disease are known to be associated with a Th2 immune response.) They did not test for the presence of viral infections, so they could not exclude or include the possibility that a chronic viral infection may underlie the immune activation, nor could they rule out a genetic basis.

The researchers cite HPA axis impairment as a

more likely explanation for the Th2 immune response. Prior research has shown that CFS patients are highly sensitive to glucocorticoids, which are "well-known Th2 driving factors," according to the researchers, and this sensitivity may "lead to increased Th2 activity."

Skowera A, Cleare A, Blair D, Bevis L, Wessely SC, Peakman M. High levels of type 2 cytokine-producing cells in chronic fatigue syndrome. *Clin Exp Immunol.* 2004;135(2):294-302.

### **Abnormal sleep and CFS**

A study by researchers at the Centers for Disease Control and Prevention reports that CFS subjects are more likely to have evidence of nonrestorative sleep and restlessness, but not sleep apnea or excessive daytime sleepiness, compared to non-fatigued subjects. Their results, say the investigators, validate other studies that indicate that CFS patients are fatigued, but not sleepy.

The study, published in *BMC Neurology* in April 2004, used a new sleep questionnaire, the Centre for Sleep and Chronobiology's Sleep Assessment Questionnaire<sup>®</sup> (SAQ<sup>®</sup>) to assess 339 subjects divided into six categories: CFS; CFS in remission; CFS-like but for medical or psychiatric exclusions; insufficient fatigue or symptoms to meet CFS criteria; fatigue in

remission; and never fatigued. The SAQ<sup>®</sup> was developed as an epidemiologic screening instrument to identify candidates for advanced sleep evaluation, but it has not yet been extensively validated.

Compared to non-fatigued subjects, CFS subjects were 28 times more likely to have abnormalities in the nonrestorative sleep factor and 16 times more likely to have abnormalities in the restlessness factor. CFS subjects who were in remission at the time of screening had significantly reduced odds for having either of these factors, which may be an important clue toward developing therapeutic interventions or assessing patient status.

One limitation of this study was that results were not confirmed by formal polysomnographic testing, but the investigators state that this will be the next step in their research. In addition they did not control for medication usage in this pilot study.

Unger ER, Nisenbaum R, Moldofsky H, Cesta A, Sammut C, Reyes M, Reeves WC. Sleep assessment in a population-based study of chronic fatigue syndrome. *BMC Neurol.* 2004, 4:6.

# Nurses Can Play Key Role in CFS Management

By Terri Lupton, RN

Chronic fatigue syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS), continues to puzzle the health care, research and patient communities. The cause of CFS is unknown and universal treatment methods have yet to be identified. Medical and nursing care is a particular challenge as new therapies are invariably a trial-and-error process.

The psychosocial implications are extensive as people with CFS make efforts to keep their lives intact while facing the stigma associated with the illness. Family, work and social relationships are often strained and the financial impact can be devastating when the illness produces significant disability. The side effects of a sedentary lifestyle, hypersomnolence and/or insomnia pose additional health risks.

CFS varies considerably in both symptom expression and severity. Some people may continue to work but must curtail home and social activities. At the other end of the continuum is the person who is disabled to the point of needing assistance in meeting basic needs.

It is estimated that 800,000 or more adults in the U.S. have CFS. Prevalence rates of this magnitude indicate that nurses are likely to encounter CFS in many settings, including the classroom. Prevalence data is not available for CFS in children and adolescents, but it should be noted that the illness has been diagnosed in children as young as age 5 years (rarely)

and in adolescents. In the under-20 population, CFS appears to occur more often in youth ages 11-17. CFS is not particularly selective: it affects blue- and white-collar workers and people of all racial and ethnic groups. It affects females at a rate of about three times that of males. Research indicates that CFS is most widespread in women ages 40-49.

## Nursing Approaches

People with CFS are aware that the diagnosis brings with it negative reactions from all segments of society; however, a particularly distressing impact may be felt when rejected by the health care community. It is imperative that CFS patients feel believed and respected. Listening with full attention and accepting the patient's account of the illness experience may be the most important actions that nurses can perform.

Nurses need to equip themselves with accurate facts about CFS. Misinformation about this illness is bountiful. Fact-based information is available from credible sources, including well-respected journals, organizations and websites. *Nursing Spectrum*, the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH) and the CFIDS Association of America are examples of reliable resources.

Fundamental knowledge of the case definition criteria is essential for nurses to help identify people with CFS. The 1994 International Case Definition for CFS was developed to provide a form of standardization for research studies. Lacking a clinical case definition, the



1994 document is used in the clinical setting to offer guidelines for diagnosis as well. However, both researchers and clinicians find the document to be insufficient in some sections. In response to this, a working group of multidisciplinary CFS experts was assembled by the CDC in 2001 to clarify ambiguities in the case definition and make it more applicable in research and clinical settings. In the clinical arena, the focus was to enhance the diagnostic process for health care providers and patients.

Diagnoses with unknown etiology are frequently subject to skepticism. A substantial body of objective evidence points to a physiological basis for the disorder; however, no specific diagnostic marker has been found. There are studies that theorize a psychological basis, yet nothing definitive has been identified in this area. When a physical basis is not readily apparent for chronic illness, there is a tendency to psychologize it. This appears to be true for CFS; attaching a mental health label is a seemingly common occurrence. Reports from CFS patients tell of numerous incidences when they have been told, "It's all in your head."

Lorraine Steefel, a senior staff writer at *Nursing Spectrum* and a core trainer for the CFIDS provider education program developed by the CDC and the CFIDS Association of America, says that even today, "I find that most RNs are unaware that CFS is a recognized disorder by the CDC and that many studies dispute the notion that it is a psychosomatic illness." Nurses can play one important role in managing CFS patients simply by being open-minded and respectful of patients. Considering all patients holistically and without preconceived assumptions is a basic nursing practice that produces benefits for all involved.

The current health care environment, coupled with today's more well-informed patients, is ideal for building a collaborative provider-patient partnership. Nurses can

create a setting in which many patients can actively contribute to their own health management. This can be accomplished by encouraging patient input, guiding patients in self-care education, providing resource information, monitoring treatment compliance and outcomes and acting as a bridge to the medical community. Sharing responsibility for personal treatment options may also decrease patient's feelings of helplessness and hopelessness. The CFS population is an excellent group with which to attempt this type of collaboration because patients are, in general, quite knowledgeable about the illness and related treatment interventions, want desperately to get well and have a sincere desire to be heard and involved.

Nurses can also act as advocates for CFS patients by raising awareness of the complexities and realities of the illness and taking advantage of educational opportunities for nursing groups, legislators and other health care providers. In summary, CFS patients are in need of the compassionate care that lies at the core of nursing philosophy. ♦

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*Terri Lupton, RN, BSS, is Coordinator for Educational Opportunities at the CFIDS Association of America. Ms. Lupton manages the CDC-sponsored primary care provider education project, "Chronic Fatigue Syndrome: A Diagnostic & Management Challenge." Critical care nursing was the major focus of Ms. Lupton's clinical nursing career, which was followed by 10 years in the field of community health education.*

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# CFS and Overlapping Conditions

By James N.  
Baraniuk,  
M.D.

A large multidisciplinary group at Georgetown has studied chronic fatigue syndrome (CFS) and allied syndromes since 1996. This work was pioneered by Dr. Daniel J. Clauw through the Georgetown University Chronic Pain and Fatigue Research Center. We have thoroughly evaluated more than 500 normal, CFS and allied syndrome subjects in an effort to identify distinct subtypes and possible risk factors within the heterogeneous CFS population. Here, we discuss some of our preliminary observations of symptom patterns and severity for 441 well-characterized subjects. These data may be useful to researchers and clinicians who care for patients with CFS and related conditions, including fibromyalgia (FM), multiple chemical sensitivity (MCS) and irritable bowel syndrome (IBS). As we expand our studies, we believe we will gain important insights into pathogenic mechanisms for various subtypes that may improve diagnosis and treatment.

Our assessment of subjects in our clinical studies at our tertiary care center has been extremely thorough and exhaustive. We have asked about symptom patterns and severity, demographic and socioeconomic status, health, nutrition, sleep, personal history and environmental factors. We measured systemic complaints, pain thresholds, allergy status, and lymphocyte and cytokine functional patterns. Lumbar punctures (spinal taps) were performed on a subgroup of symptomatic and normal subjects in order to examine the cerebrospinal fluid that bathes the brain and spinal cord. Standard questionnaires and measurement tools have been used consistently over the six years of accumulating this massive data set.

To classify patients in various sub-

groups, we used accepted criteria for CFS, FM and MCS. CFS was applied to patients who fully met the 1994 International CFS case definition (Fukuda, et al). FM was defined using the American College of Rheumatology criteria published by Wolfe et al, using finger pressure and dolorimetry to test tender points. The Simon criteria were used to classify patients with MCS. Patients were grouped into seven categories: CFS (only), CFS/MCS, CFS/FM, CFS/FM/MCS, MCS (only), FM (only) and normal. Table 1 (see page 8) shows the number, percentage, age and sex of subjects in each subgroup.

At intake all subjects were asked to rate symptom severity “in the past six months” as 0 (none), 1 (trivial), 2 (mild), 3 (moderate) or 4 (severe). Previous statistical analysis showed that “trivial” was a critical element to account for relatively low-intensity, nondisruptive symptoms in contrast to more consistent, persistent and bothersome “mild” symptoms. “Severe” and “extremely severe” were collapsed into one level. Scores for fatigue plus the eight CFS symptom criteria were totaled to yield a severity sum ranging from 0 (none) to 36 (most severe).

## Distribution and severity of CFS symptoms

The subjects in these studies were recruited for several different reasons, including the examination of low back pain, fibromyalgia, Persian Gulf syndrome, allergic rhinitis, sinusitis and CFS. Overall, CFS was present in 43 percent of our subjects. Many of these had overlap with FM and MCS. Only about 10 percent of the subjects had either FM or MCS alone. The female predominance of those who meet the CFS case criteria was apparent. The

control population also had a high proportion of females so that the results of male subjects did not skew the findings for the normal group. This made it possible to understand some of the effects of gender on the outcomes we measured.

As expected, fatigue was moderate to severe in each CFS group and was significantly higher than the MCS (only), FM (only) and normal groups. The most surprising finding was that the sum of the CFS symptom severity score was highest for the CFS/MCS group (24.0) and lowest in the FM (only) group (5.6). Several statistically significant relationships were found, as displayed in Table 1. These preliminary data need to be further analyzed in order to better understand their implications for diagnosis and treatment.

### **Prevalence of IBS**

Following classification into the seven groups, we assessed these subjects for the presence of irritable bowel syndrome (IBS). Standardized questionnaires were used to make this diagnosis. We propose that IBS may involve neural dysregulation of intestinal function. Abnormal nerve signals may cause disordered peristalsis leading to diarrhea and constipation subtypes. We wanted to see

how common IBS was in the seven subtypes. The CFS/FM/MCS subgroup had the highest rate of IBS at 69 percent. Only 3 percent of normal subjects had IBS. Of the other symptomatic subgroups, MCS (only) patients had the lowest prevalence, with 18 percent meeting criteria.

### **Irritant rhinitis syndrome (IRS)**

IRS is a nonallergic disorder of dysfunctional nociceptive nerve sensitivity to inhalant chemicals. We have shown that airborne chemical irritants can stimulate “nociceptive” pain-carrying nerves to lead to sensations of pain, nasal congestion, blockage and rhinorrhea (drip). These nerves release neuropeptides such as substance P in the nasal mucosa by the axon response mechanism. This causes glandular secretion in humans. This is a very rapidly acting defense mechanism that responds to potentially dangerous inhaled materials by causing the release of the gummy mucus that can bind and neutralize the inhaled material. The glandular secretions also contain many antimicrobial and innate immune system factors that help prevent infections. Very intense mucosal irritation activates central parasympathetic reflexes

## **DEFINING SUBSETS**

Most CFS researchers agree that CFS is a heterogeneous condition and that patients meeting the CFS case definition may be classified in various subtypes; however, there has been little accord in defining subtypes. In research, the particular hypothesis may drive the selection criteria. For example, studies looking at the relationship of an infectious agent to CFS, such as mycoplasma, may subdivide patients by type of onset—sudden or gradual. Studies of cognitive impairment have grouped subjects according to history of past or current mood disorders. Treatment trials frequently stratify by the presence or intensity of specific symptoms or illness features.

With so many different ways to split the population, it’s imperative that research reports describe selection criteria and classification measures. Unfortunately, this important information is often glossed over or omitted altogether, either by the authors or the editors. Our understanding of CFS suffers as a result.

that cause cholinergic glandular secretion. The volume of secretions contributes to the sensations of blockage to airflow and rhinorrhea.

We examined the factors that caused CFS and control subjects to have nasal complaints. An “irritant rhinitis questionnaire” was developed to quantify the severity of nasal congestion and discharge in response to eight irritating factors. The most significant factors were weather changes, strong odors (perfumes, hairspray, cleaning solvents) and tobacco smoke. The results are consistent with a condition formerly known as vasomo-



**TABLE 1: Georgetown database of 441 subjects**  
(means with rigorous significance levels)

	CFS	CFS/MCS	CFS/FM	MCS	CFS/FM/MCS	FM	Normal
<b>Number</b>	<b>92</b>	<b>56</b>	<b>34</b>	<b>20</b>	<b>17</b>	<b>13</b>	<b>209</b>
<b>Age</b>	<b>43.8</b>	<b>45.3*</b>	<b>43.2</b>	<b>39.2</b>	<b>43.1</b>	<b>46.8</b>	<b>37.8</b>
<b>% Male</b>	<b>25%</b>	<b>5.4%</b>	<b>24%</b>	<b>25%</b>	<b>12%</b>	<b>38%</b>	<b>38%</b>
<b>CFS Severity Score</b> 0 to 4 point severity scale for each CFS criterion for the past 6 months; criterion scored as 0 (none), 1 (trivial), 2 (mild), 3 (moderate), 4 (severe)							
<b>Fatigue</b>	<b>3.4</b>	<b>3.6</b>	<b>3.3</b>	<b>1.0</b>	<b>3.6</b>	<b>0.31</b>	<b>0.72</b>
<b>Cognitive function</b>	<b>2.1</b>	<b>2.9</b>	<b>1.5</b>	<b>1.3</b>	<b>2.2</b>	<b>1.3</b>	<b>0.62</b>
<b>Sleep</b>	<b>2.7</b>	<b>3.4</b>	<b>1.4</b>	<b>1.9</b>	<b>2.3</b>	<b>0.71</b>	<b>0.83</b>
<b>Exertional exhaustion</b>	<b>2.3</b>	<b>3.0</b>	<b>1.4</b>	<b>1.1</b>	<b>2.4</b>	<b>0.14</b>	<b>0.35</b>
<b>Sore throat</b>	<b>1.2</b>	<b>1.7</b>	<b>0.50</b>	<b>0.59</b>	<b>1.0</b>	<b>0.14</b>	<b>0.33</b>
<b>Sore nodes</b>	<b>0.92</b>	<b>1.3</b>	<b>0.82</b>	<b>0.94</b>	<b>1.1</b>	<b>0.29</b>	<b>0.14</b>
<b>Sore muscles</b>	<b>2.3</b>	<b>3.2</b>	<b>1.9</b>	<b>1.4</b>	<b>2.4</b>	<b>1.3</b>	<b>0.53</b>
<b>Sore joints</b>	<b>1.9</b>	<b>2.5</b>	<b>1.4</b>	<b>1.1</b>	<b>2.3</b>	<b>0.71</b>	<b>0.40</b>
<b>Headache</b>	<b>2.0</b>	<b>2.7</b>	<b>1.3</b>	<b>1.8</b>	<b>1.8</b>	<b>0.50</b>	<b>0.66</b>
<b>Sum (0 to 36)</b>	<b>18.7</b>	<b>24.0</b>	<b>13.4</b>	<b>11.1</b>	<b>18.8</b>	<b>5.6</b>	<b>4.6</b>
<b>Prevalence of Irritable Bowel Syndrome (IBS, Rome 1 criteria)</b>							
<b>IBS</b>	<b>40%</b>	<b>50%</b>	<b>33%</b>	<b>18%</b>	<b>69%</b>	<b>38%</b>	<b>3%</b>
<b>Irritant Rhinitis Score (IRS)</b>							
<b>Congestion (0 to 32)</b>	<b>9.3</b>	<b>14.0</b>	<b>4.8</b>	<b>11.6</b>	<b>16.9</b>	<b>-</b>	<b>4.3</b>
<b>Drip (0 to 32)</b>	<b>4.9</b>	<b>7.7</b>	<b>5.2</b>	<b>8.1</b>	<b>6.2</b>	<b>-</b>	<b>3.3</b>

tor rhinitis or nonallergic rhinitis. The CFS/FM/MCS and CFS/MCS subgroups had the most severe complaints and highest prevalences of IRS. The mechanism responsible for irritant rhinitis is most likely a problem in nerve sensitivity. It is not an allergic problem. The levels of the antibody of allergy, IgE,

and the rate of positive allergy skin tests are measures of true allergic diseases. The levels were the same in CFS and control subjects demonstrating that CFS subjects could have regular allergic problems, but that allergies alone were not a cause of CFS.

**Implications**

There is considerable overlap of CFS with allied syndromes of FM and MCS. This overlap may explain why studies that classify subjects only by CFS status can show a wide range of results since the influence of mechanisms of FM or MCS may not be taken into account in the “CFS” responses. The same critique applies to FM studies that do not stratify by CFS status. MCS is generally not examined in these studies because there is controversy over the ways to define this syndrome. We propose that the molecular mechanisms of fatigue (CFS), pain (FM) and irritant sensitivity (MCS) may be distinct, and that different patterns of these symptoms and their underlying mechanisms may account for the wide variations in severity and symptoms in CFS subjects. We hope that our investigations will identify these mechanisms and lead to better diagnosis and dramatically new and insightful treatments.

For the clinician managing CFS patients, evaluation of possible coexisting conditions is equally important. For example, treatment approaches may differ depending on the presence of MCS or IBS. The patient with MCS may have increased sensitivity

to medications and might therefore need to start with extremely low doses that are cautiously increased to tolerance. They may also need to be educated about avoidance strategies to reduce symptom exacerbations brought on by exposure to certain substances. The CFS patient with IBS might benefit from new medicines that treat IBS and may need to regulate diet more carefully to improve daily function. For example, the new fiber wafers can be incorporated into one's diet as a bread substitute and to replace liquid stool softeners. Nasal complaints respond very well to frequent use of over-the-counter nasal saline sprays that can be used whenever symptoms become bothersome. This reduces the reliance on other medications and even potential sinus surgery that may make the problems even worse. Application of Nose Better Gel<sup>®</sup>, Vaseline or other appropriate products into the nasal cavity can also help reduce the impact of airborne irritants and coat the lining of the nose to prevent bleeding and nasal irritation.

We hypothesize that the subtypes of CFS have distinct patterns of pain and psychometric, personal environmental and lifestyle characteristics. Using statis-

tical model outcomes, we hope to reveal underlying commonalities that give insights into disease mechanisms and risk factors. We are also trying to secure funding to extend initial investigations of cerebrospinal neurotransmitters, urine markers and proteomics in CFS that we believe will yield important advances in pathophysiology, diagnosis and treatment. ♦

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## Research Q&A

# Occupational Therapy for CFS

By Vicki Walker

**R**enee Taylor, Ph.D., is an associate professor in the University of Illinois at Chicago's Department of Occupational Therapy. Dr. Taylor's research focuses on developing community-based treatment programs for individuals with chronic fatigue syndrome (CFS).

She has applied her expertise to the development of the CFS Empowerment Project, a peer-based intervention strategy for CFS patients delivered through a Center for Independent Living. Many of the project's elements are based on occupational therapy (OT) strategies, with the goals of improving overall quality of life, functional capacity, illness severity, coping and service utilization among individuals with CFS.

Despite its name, occupational therapy is less about the workplace than it is about helping people become more functional in the most important aspects of their lives, a primary goal of all CFS treatment. Even so, it is infrequently used by CFS clinicians and patients. In this interview, Dr. Taylor explains how OT can help people with CFS and why it might be considered more often.

### *Q: How can OT help people with CFS?*

**Dr. Taylor:** For people with CFS, occupational therapy can facilitate participation in roles, activities and sometimes work that individuals find motivating, meaningful and gratifying. Occupational therapists can assist people with CFS in many areas including:

- identifying personal and work activities that are inspiring, possible to do and meaningful
- renegotiating, renewing and forming new social roles within families and social networks
- establishing new habit patterns that

enable stable functioning and reduce the risk of relapse or symptom escalations

- evaluating what a person with CFS is able to do in terms of personal care and mobility
- determining how and whether an individual can perform these activities safely and competently on a regular basis
- adjusting an individual's home, community and work environments to promote safety and energy conservation

### *Q: What has research shown about the benefits of OT for people with CFS?*

**Dr. Taylor:** There has been very limited research on the efficacy of OT for people with CFS. However, case study reports and studies of programs that incorporate OT as part of an integrative or multidisciplinary approach to rehabilitation have found that certain strategies taught by occupational therapists can lead to improved quality of life, improved motivation and increased participation in personal, social and work settings.

As more people with CFS and their health care professionals become aware of the many possible benefits of OT, it is hoped that increased use of these services by individuals with CFS will lead to additional, large-scale research studies and funding for OT programs.

### *Q: What kind of assessments might an occupational therapist do for a person with CFS?*

**Dr. Taylor:** A therapist might use any number of assessments, depending on his or her perspective and the client's personal goals and reasons for consulting an occupational therapist. Assessments can evaluate things like cognitive performance, physical

capacity, motivators, habit patterns, life roles, physical safety, mobility and social supports and networks (Barrows, 1995; Kielhofner, 2002; Taylor & Kielhofner, 2003; Taylor et al., 2003).

One such assessment is Diane Barrows's *Functional Capacity Evaluations* (Barrows, 1995). Barrows is an occupational therapist who has made extensive contributions to knowledge in the area of functional capacity evaluation for individuals with CFS. Typically, functional capacity evaluations can take from six hours to several days to get an accurate picture of the mental and physical capabilities of someone with CFS. It is important that these evaluations are done over a period of several days so that declines in endurance and reactions to exertion over time can be observed and documented.

These assessments evaluate both physical and cognitive abilities. In terms of physical abilities, the occupational therapist can formally evaluate fitness status, motor coordination, joint range of motion, muscle strength, grasp strength, endurance, handling of materials and dexterity. In addition, a therapist can observe other abnormalities such as pain behaviors, presence of tremor, ease and pattern of movement and signs

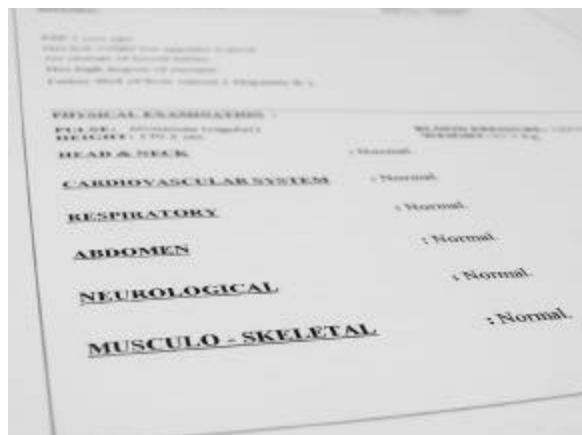
of muscle atrophy.

In terms of cognitive abilities, an occupational therapist can evaluate basic cognitive functions involving attention span, concentration, memory and numerical processing. In addition, reasoning, abstract thinking and judgment can be assessed (although more advanced cognitive assessments should be conducted by a neuropsychologist familiar with CFS). More information about specific tests can be found in Barrows (1995).

**Q: What kinds of interventions might an occupational therapist prescribe?**

**Dr. Taylor:** Occupational therapists can draw upon a number of theories, technologies and areas of skill and knowledge. These include remotivation training to support engagement in physical and mental activity (Kielhofner, 2002); assistive devices such as scooters, canes and grab bars for mobility and balance, or bed wedges for comfort and to condition individuals with orthostatic intolerance; and memory and organization enhancers like calendars, Post-It notes and Palm Pilots.

Treatment approaches vary depending on the occupational therapist's orientation toward treatment and the client's goals (Cox,



Taylor & Kielhofner, 2003; Taylor et al., 2003). Some of the more common approaches include:

- Goal setting
- Activity pacing
- Energy conservation training
- Ergonomics training
- Assistive devices and training
- Graded activity training
- Remotivation therapy
- Transportation training
- Vocational rehabilitation
- Evaluation and training in performing self-care activities and activities of daily living, such as cooking, housework and financial management
- Education about CFS for the client and family members
- Education about available resources from public and private funding sources

**Q: When should a clinician refer a patient to OT?**

**Dr. Taylor:** Any time he or she observes that a patient

is having difficulties with self-care, mobility, motivation or engagement in meaningful activity or work.

**Q:** *How could a doctor use an occupational therapist's report?*

**Dr. Taylor:** A clinician can get a lot of information from this report. Some possibilities include information about a client's interests, hobbies, habits and social and occupational roles; physical and cognitive capabilities; and ability to care for his or her basic needs.

**Q:** *If a patient can't see an occupational therapist because of insurance, financial and/or mobility concerns, are there any OT techniques a primary care doctor could use?*

**Dr. Taylor:** Yes, a primary care physician might prescribe any of the above-mentioned techniques, if appropriately educated and trained on how to administer them. However, expecting a primary care provider to perform these treatments may be unrealistic for some physicians given the tight time schedule they may be facing. This is why referral to occupational therapy—and advocacy for insurance coverage for occupational therapy—are as important as training physicians in administering treatments

that are also used by occupational therapists.

**Q:** *What is the CFS Empowerment Project?*

**Dr. Taylor:** This project is a peer-facilitated, multidisciplinary rehabilitation program that aims to improve quality of life and access to resources for individuals with CFS. This program was funded by the National Institute on Disability and Rehabilitation Research through a grant awarded to me and Dr. Leonard Jason of DePaul University. It is a yearlong program comprised of CFS management groups and one-on-one peer counseling (Taylor & Jason, 2002).

A recent, randomized clinical trial (Taylor, 2004) demonstrated that the program is effective in improving quality of life for individuals with CFS. Although funding for this project is now over, one expectation is that the project can be reinitiated at any Center for Independent Living, or it can be initiated in a self-help format. Information about this project, a resource directory and the program curriculum can be found online at [www.ahs.uic.edu/ahs/files/ot/bookler/CFS\\_Website/index.htm](http://www.ahs.uic.edu/ahs/files/ot/bookler/CFS_Website/index.htm).

**Q:** *What have you learned from the CFS Empowerment Project that is useful*

*to the clinical management of CFS?*

**Dr. Taylor:** Some of the most useful aspects to the clinical management of CFS emerging from the CFS Empowerment Project include the importance of self-directed goal setting and support for goal attainment, availability of resources and social support networks. It is important for individuals with CFS to become educated about their rights under the Americans with Disabilities Act, as well as their rights to access certain benefits and resources available to individuals with chronic illness and disabilities. ♦

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*Vicki Walker is the former editor of the CFIDS Chronicle.*

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## Reader survey, *continued*

### Interest areas

Please rank the following topics/features based on your interest level. Place a 1 next to the topic you are most interested in, a 2 next to the second-most interesting, etc., with 12 being the least valuable.

- Research Q & A (interview with researcher)
  - Research briefs
  - Case studies
  - Patient care articles
  - Highlights of CFS conference presentations
  - Feature articles on pharmacologic treatment approaches (i.e., latest on SRIs)
  - Feature articles on CFS symptoms (i.e., postexertional malaise, persistent pain, sleep problems)
  - Information on overlapping conditions (i.e., FM, MCS, Lyme disease)
  - In-the-trenches articles written by clinicians who treat CFS patients
  - Information about research grants available through the CFIDS Association
  - Information on continuing CFS educational opportunities for CE, CME, CEU or CNE credits
  - Other \_\_\_\_\_
- 

### Readability & Design

I usually find articles in the *CFS Research Review* (check all that apply):

- Too technical
- Too long
- Not scientific enough
- Too short
- Easy to read
- Should be more visually appealing
- Need more photos
- Don't need to have fancy graphics to make me want to read them
- Need more charts and graphs

#### Proposed Change

Here is a suggestion for reformatting that we are seriously considering.

What do you think?

- Very appealing
- Very unappealing
- Doesn't matter to me

Change to a CFS Provider Tool Kit. Focus on one subject in each publication (CFS and sleep, CFS and the immune system, CFS and cognitive difficulties, etc.). For instance, an issue on the topic of CFS and pain might include an article from a clinician on treatment approaches, an overview of major research studies on the topic, a checklist of key facts, treatment protocols, an annotated bibliography on the topic, etc. Each issue would be placed in your CFS tool kit for future reference as needed.

### Contact Information (Optional)

Your name \_\_\_\_\_

Your address \_\_\_\_\_

Telephone \_\_\_\_\_

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Please mail this survey to: The CFIDS Association of America, Research Review Survey, PO Box 220398, Charlotte, NC 28222-0398. You may also fax it to 704-365-9755.

# What Do Physicians Think about CFS?

By Marcia  
Harmon

There is much anecdotal evidence, especially from the patient community, about the perceptions those in the medical community have regarding CFS. Because helping the medical community detect, diagnose and manage CFS is part of our mission, the Association recently commissioned some research to find out directly from primary care physicians what they think about this illness.

Two focus groups were conducted in Alexandria, Virginia, in September 2003 with 8 female and 12 male primary care physicians, who answered a number of questions designed to detect perceptions about CFS. (The doctors who participated were not CFS experts.) The research showed that while attitudes have certainly changed in the past decade, there is still a lot of confusion, a lack of training and a high level of frustration that is impacting patient care.

One key finding from the focus group research is that CFS is a last-resort diagnosis doctors are very reluctant to make. A number of reasons were given by various participants:

- Diagnosis is like a death sentence for patients. They lose hope. They're not going to die, but you have to work real hard to convince them of that.
- CFS is a lay diagnosis. I won't legitimize an illness that is not backed up by fact. CFS is not a fact; cancer is a fact.
- Diagnosing CFS makes patients feel like a victim. It can lead to the "Why me?" syndrome.

While some of the doctors in the focus groups believe CFS is a real physiological disease, they are nevertheless governed by the notion that a CFS diagnosis is so devastating to patients that it makes them despondent and less likely to recover. This attitude has far-reaching consequences. First, if CFS

is not diagnosed and treated successfully within the first five years, it becomes a life-altering condition that a patient is likely to live with for many, many years. (Treatment in this context means treating symptoms such as sleep problems, pain, depression, headaches, etc. since there is no known efficacious treatment protocol for CFS.) Second, avoiding the diagnosis creates a cycle of frustration for both doctors and patients as patients return over a period of months and years for treatment. And third, patients themselves prefer to have a concrete diagnosis, allowing them to marshal their physical and emotional resources to fight a specific threat instead of never knowing what's wrong with them.

The focus group findings also suggest that doctors need to consider whether their reluctance to diagnose CFS is, in part, a projection of their professional inadequacy. The participants were largely at a loss concerning how to treat CFS patients and, as a result, prefer not to handle such cases. Key statements included:

- I am adequately trained to diagnose CFS, but not to treat it. I know of no effective treatment.
- My job is to fix people, and with CFS, I am often ineffectual. CFS is frustrating because we can't give them relief.
- CFS negates the personal satisfaction I look for as a doctor.

These findings suggest that for CFS patients to receive good care from the physicians they desperately seek out for help, doctors need to find ways to handle their own frustrations with this illness.

All the news isn't bleak. Look for more findings from the physician focus groups in the next issue of the *CFS Research Review*. We'll also be covering findings from our general public focus groups in the next *CFIDS Chronicle*.

## Help the PERSON behind the SYMPTOMS



### Chronic Fatigue Syndrome: A Diagnostic & Management Challenge

Chronic fatigue syndrome (CFS) affects at least 800,000 U.S. adults and teens with debilitating pain, exhaustion and cognitive problems.

Studies show that 80% of people with CFS have not been properly diagnosed by a medical professional. Even fewer receive appropriate medical care.

#### Earn Free Continuing Education Credits from CDC

Self-study courses about diagnosing and managing CFS are available in Web-, print-, video-based formats.

The CDC is an accredited provider of continuing education credits for various professions.

For more information:  
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A collaborative effort of  
The Centers for Disease Control and Prevention (CDC)  
and The CFIDS Association of America

## 1994 INTERNATIONAL RESEARCH CASE DEFINITION OF CHRONIC FATIGUE SYNDROME\*

CFS is a syndrome characterized by fatigue that is:

- Medically unexplained
- Of new onset
- Of at least six months' duration
- Not the result of ongoing exertion
- Not substantially relieved by rest
- Causes a substantial reduction in previous levels of occupational, educational, social or personal activities

In addition, there must be four or more of the following symptoms:

- Impaired memory or concentration
- Sore throat
- Tender neck (cervical) or armpit (axillary) lymph nodes
- Muscle pain (myalgia)
- Headaches of a new type, pattern or severity
- Unrefreshing sleep
- Postexertional malaise (lasting more than 24 hours)
- Multijoint pain (arthralgia without swelling or redness)

Conditions that would exclude a diagnosis of CFS include other medical disorders known to cause fatigue, major depressive illness, medication that causes fatigue as a side effect, and alcohol or substance abuse.

*\*Fukuda et al, The chronic fatigue syndrome: a comprehensive approach to its definition and study, Ann Intern Med, 1994; 121:953-59.*

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