

# 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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