

There are no easy answers for people struggling with crippling and long-term effects of CFIDS. This article explores the lack of scientific research on severely ill PWCs and offers some tips for coping with this life-altering illness.



Living with Severe CFIDS

By ANGETTE RICE-FIGUEROA, DIRECTOR OF PUBLICATIONS

Stories about people with CFIDS who have returned to work or can prepare a meal or even leave their beds are considered encouraging success stories by most PWCs. For those PWCs who remain housebound or bedridden, however, such stories can seem like fairy tales. Too many of the “good” stories leave the severely ill members of the CFIDS community feeling invisible and forgotten. These long-time sufferers yearn for information about the subset of the CFIDS population that is severely ill.

Unfortunately, little evidence-based research exists on this group. We don’t even know what percentage of the CFIDS community is considered severely ill or precisely what defines severe CFIDS. There are no studies or statistics or facts and figures to support any theory about the most seriously ill PWCs.

One of the only groups formed specifically to support the severely ill is the United Kingdom’s 25% ME Group. The “25%” in its name refers to the group’s belief that 25 percent of the people in the United Kingdom suffering from CFIDS/ME are severely ill.

A 2002 report written by Europe’s chief medical officer (equivalent to the United States surgeon general) defines the severely ill as

“patients whose physical disability is most severe, leading to serious restrictions in mobility and functioning. In many, these restrictions are accompanied by other markers of severity, such as cognitive impairment or prolonged course.”

Some studies in the United States have examined illness duration or symptom severity, but there has been no large-scale study of the severely ill PWCs in America that would help guide treatment protocols, improve functionality or suggest new avenues of research.

Obstacles to research

Considering the functional limitations this population endures, it’s understandable why it’s nearly impossible for severely affected PWCs to visit a doctor regularly or to participate in laboratory research. Dr. Benjamin Natelson of the New Jersey Chronic Fatigue Syndrome and Fibromyalgia Center, and professor of neurosciences at the New Jersey Medical School, said that it’s difficult to conduct research with the severely ill and, therefore, hard to offer new ideas about treatment and recovery.

“The issue limiting research on this class of patients is the nature of the illness itself,”

said Dr. Natelson. "If they are severely ill they are unable to regularly see a doctor and are not accessible for research. If they are unable to come into a laboratory setting, the only research possible will be that done via telephone, the Internet or the mail, and even that activity might be too taxing on a patient."

Another CFIDS expert, well-known physician Dr. David Bell, agrees with this assessment. "I recently completed a 20-year follow-up study on children I'd treated, and one patient told me over the phone that she was too sick to complete the questionnaire," he said. "It would've taken only about 20 minutes for a healthy person to complete that task."

Even those patients who can make it to the lab might get there only to be excluded from research due to their limited cognitive functions, the presence of other medical conditions or the inability to stop taking their prescribed medications.

For some patients even getting to their doctor for routine visits is a challenge, further reducing the scientific and clinical information available about severely ill PWCs. Based on his own experience treating hundreds of CFIDS and FM patients, Dr. Chuck Lapp of the Hunter-Hopkins Center in Charlotte believes that severely ill PWCs need close supervision of medications, should have supportive counselors and need close follow-up by their doctors. These are processes often impossible to complete successfully when patients are so ill they can't make regular office visits.

"People have told me that going to the doctor just isn't worth it because of the postexertional relapse," agrees Dr. Bell. "After years of being ill, many PWCs become discouraged, depressed and confused, and they don't know who to trust anymore."

In spite of the difficulty and

wary feelings, Dr. James Jones of the Centers for Disease Control and Prevention in Atlanta says that following up with a doctor is essential for many reasons. "PWCs who have had a CFS diagnosis for 10 years or more need to get a new evaluation of their condition and of their medications," said Dr. Jones. "It's key to have updated thorough medical and psychological evaluations with a doctor who is a true believer in this illness."

Dr. Jones went on to stress that a reevaluation is critical in identifying any possible underlying diseases or co-infections that might require treatment. Also important is recognizing the components of the illnesses that are affecting a patient, and making sure those components are addressed individually.

How to evaluate medical treatments

While there is currently no cure for CFIDS or FM, there are many credible and not-so-credible treatments for the symptoms of these illnesses. Some PWCs feel as if they've tried them all. However, the willingness to try anything new in the hope of gaining relief can actually be dangerous, leading some people to explore unproven remedies and gimmicks.

Individuals with CFIDS and FM need to be discriminating when choosing a treatment. What works for someone else may not work for you. If there was one "magic" or "harmless" cure, everyone would've used it by now. Writer and PWC Lisa Lorden offers the following tips to help you decide whether a treatment is worthwhile for you and to assist you in avoiding quack cures.

■ **Expect some proof.** Look for treatments that have some scientific evidence of effectiveness, such as those backed by clinical research trials. Testimonials from patients

who have been "cured" are not legitimate proof.

■ **Do your homework.** Research therapies you are considering as much as you can. Good places to go for information are credible online resource centers and the *CFIDS Chronicle*. Always consult with your health care providers before beginning new treatments.

■ **Be critical about marketing.** Beware of remedies that are promoted through multilevel marketing, tabloid articles or mail-order offers. Also avoid remedies described as "secret formulas," "exclusive" or "special." Legitimate scientists don't keep their findings secret or exclusive.

■ **Beware of promises and claims.** Be suspicious of ads for treatments that claim to have no side effects. Also beware of claims that the product can completely relieve pain, eradicate all symptoms, take effect the first time you use it or give you unlimited energy.

■ **Talk to fellow PWCs.** Visit support groups or online discussion groups to find out about other people's experiences with a particular therapy. You can contact the CFIDS Association of America's resource line at 704-365-2343 for a list of support groups in your area.

■ **Keep records.** If you do decide to try something new, keep a record of your symptoms before and throughout treatment so you can track any changes in your health. Improvement may be subtle and difficult to recognize otherwise.

■ **Save some time.** In his article, "What a Pain" in the winter 2005 *Chronicle*, Dr. Alan Spanos says that new pain treatments should be tried with as brief a trial as is necessary to see if it helps or not. Dr. Spanos cautions that most pain medications work within 1-14 days,

so trying a new treatment for weeks wastes time and money and may be dangerous. Be sure to stop any new treatment early if you begin to experience serious side effects—another reason to inform your physician in advance, so he can help you determine when or if it's time to stop.

Coping strategies

After taking the medical steps necessary to manage your illness, consider evaluating the emotional and behavioral methods you use to battle CFIDS.

You're probably tired of hearing that you need an effective coping method, but coping skills are some of the best weapons against the ongoing ravages of CFIDS.

"Hope for improvement is the single-most fundamental thing that a PWC should learn to develop and maintain," said Dr. Renee Taylor of the University of Illinois at Chicago. According to Dr. Taylor, severely disabled PWCs can develop and maintain hope in a number of small, emotionally fulfilling ways:

- Take note of small nuances in the behavior of the syndrome. On days when there is even the slightest

positive sign of improvement (i.e., the absence of just one of many difficult symptoms), document that change in a journal. Maintaining a journal containing only notes about the absence of symptoms provides a reminder that the course of CFIDS does change over time and that periods of modest improvement are possible. The journal can also be used to document positive responses to treatment.

- Beyond just being aware of any slight improvements, capitalize on times when you feel a little better. Utilize any possible window of relenting symptoms to indulge in something pleasurable, like taking a warm bath, listening to your favorite music, calling a friend or watching a movie. The more pleasurable, gratifying and fulfilling elements you add to your life during less symptomatic times, the more likely you are to maintain hope for improvement in the future.

- On days when you feel strong enough, try an activity. The activity doesn't have to involve movement, it can be as simple as having a friend come sit with you for an hour.

- Advocacy efforts may also contribute to your emotional well-being. You are not without a voice because you're housebound or bedridden. You might be strong enough to write to Congress about research dollars or to engage in an online awareness advocacy activity on your own. If you don't feel up to the task, encourage your family, friends and health care providers to be your voice and to advocate on your behalf.

Coping with a catastrophic chronic illness is an ongoing process, not a one-time technique. There is no one-size-fits-all solution. If you're up to offering tips for living as a long-term PWC, or if you'd like to share your story in the *CFIDS Chronicle* or the *CFIDSLink* e-newsletter, we'd like to hear from you.

We'd also like to hear ideas from our readers on tackling the very difficult issue of research specific to the severely ill. Please reply to mharmon@cfids.org. ■

EXPLORING THERAPIES? TRY REMEDYFIND, AN ONLINE RESOURCE.

Remedyfind (www.remedyfind.com) is an online membership community where individuals suffering from a wide range of nearly 50 medical conditions can share information about treatments that have worked, and those that didn't. Founder Brett Hodges, a recovering person with CFIDS (PWC), created the site to help pool the firsthand knowledge and experience of people trying to sort out the ever-widening array of therapy choices. "When I was first ill, I tried a multitude of different treatments—drugs, diets, counseling, alternative medicine and bodywork techniques. Some helped more than others. Few physicians knew what to do for me, and alternative practitioners were more confident—but not always objective—about their recommendations. One of the most useful tools I found was keeping a journal of my reactions to the different treatments

I tried, rating each one for its effectiveness, side effects, etc. When I thought more about it, I realized that this might be useful information for others too. That was the inspiration for creating the Remedyfind site," Brett recalls.

The site is not owned, sponsored or supported by any industry organizations, and Remedyfind fiercely protects the privacy of its members. Users, including patients and health care providers, rate the effectiveness of prescription drugs, over-the-counter products, self-care therapies, supplements and procedures. The top 10 remedies are listed with their weighted ratings and numbers of raters. Clicking on each treatment sends you to a detailed description of that product or approach. Newsletters on a variety of health conditions are also offered, and all of this valuable information is free.