

# Clinical Care for CFS

*Because chronic fatigue syndrome is so complex, it can be challenging to manage, creating a cycle of frustration for patients and physicians alike. Here, thanks to the assistance of a panel of top CFS physicians, we offer some insight into best practices that can help break this vicious cycle.*

By Marcia Harmon, Director of Communications, CFIDS Association of America

While most clinicians and researchers in the field of chronic fatigue syndrome would agree that scientific advances in our understanding of the illness have been significant over the past two decades, there is far less enthusiasm about progress in clinical care. There are a number of factors involved, not the least of which is that most research to date has focused on cause not cure, or treatment. The fact that very few physicians specialize in the care of CFS patients and can contribute to the body of knowledge on clinical care has also slowed progress. Coupled with these factors is the growing recognition that there are subsets of CFS patients, and what works for one set of patients may be of little benefit to another group.

That doesn't mean there haven't been countless proposals to treat CFS with medicines, dietary and herbal supplements, exercise strategies, behavioral and coping interventions and alternative therapies. A quick Internet survey of books on the subject and websites touting various curative protocols offers a dizzying array of options.

But what are the current best practices when it comes to treating CFS? What is the standard of care? What therapeutic interventions work best for the greatest number of patients?

In this article we offer an overview of these issues. To help us, we solicited information and guidance from several top clinicians in the United States, and we thank them for agreeing to be on our panel and share their time and expertise:

- Dr. Lucinda Bateman, Fatigue Consultation Clinic, Salt Lake City
- Dr. David Bell, Primary Care Pediatrics, Lyndonville, New York
- Dr. Nancy Klimas, University of Miami Medical

School, Miami, Florida

- Dr. Charles Lapp, Hunter-Hopkins Center, Charlotte, North Carolina

- Dr. Susan Levine, internal medicine practice, New York City

- Dr. Dan Peterson, Sierra Internal Medicine, Incline Village, Nevada

- Dr. Alan Pocinki, internal medicine practice, Washington, DC.

## Team approach to treatment

Because CFS is such a complex multisystem illness, these clinicians all agree that integrative care is a desirable model. Having a team of health care professionals—including psychologists, endocrinologists, physical therapists, occupational therapists and others—who can collaborate on achieving the best therapeutic outcome is ideal. Achieving that ideal is somewhat problematic, however, because



there are so few specialists across the country who know enough about CFS to contribute to the team. Pocinki, whose practice consists of 5% CFS/FM patients, explains, "I'd love to have more of a team approach, but I can't find any teammates. Unfortunately, a physical therapist who doesn't understand CFS is worse than none at all. Similarly, a psychologist who treats these patients as if they're just depressed usually does more harm than good."

Bell has a similar experience. "My practice is rural and located about an hour away from the closest specialists, so access to integrative care is a problem." Also, Bell says many of his patients come from other parts of the country or Canada, and since he doesn't know who the local specialists are in all these cities, "referring patients to someone who doesn't understand CFS is frequently a disaster."

Bateman is a proponent of using a multidisciplinary team approach to manage CFS and FM and integrates Patricia Fennell's Four-Phase Model into patient care. (See the summer 2005 issue of the *CFS Research Review*.) She says "patients can benefit from the involvement of a team of primary and allied health care professionals in managing the physical, social and psychological effects of the illness."

Assembling such a team takes time and commitment, and is easier in metropolitan rather than rural practices. "The Hunter-Hopkins Center has a number of strategic alliances with local psychologists, physical therapists, psychiatrists and other specialists we know are understanding and knowledgeable about CFS," Lapp says of his Charlotte clinic. "We attempt to maintain close relationships and educate these professionals about CFS and FM."

In Miami, Klimas says, "It's not that these specialists don't exist, it's that managed care limits who patients can see." Levine agrees. "My referral pattern depends on whether their insurance allows for services from other providers such as psychologists, physical therapists or acupuncturists. I do have a team in New York that I try to incorporate into most of my patients' care, even if they only do an initial consultation."

Peterson, who also has difficulty finding knowledgeable specialists, believes this is just one more reason that the Center for Excellence concept is so appropriate for CFS care. Even after more than 20 years in the field, he says, "I can't possibly understand everything there is to know about CFS. It's just far too complex and multisystemic. It doesn't fit the current model for managed care, and the

## FAST FACTS

### Managing Medications and Supplements

- Clinicians may need to systematically try various and multiple drug interventions to determine which works best for symptom management. A drug that is effective for one CFS patient may be ineffective for another.
- Find the most effective and cost-effective medication regimen. Prescribe single drugs that treat multiple symptoms whenever possible. For instance, choose meds for sleep and mood that also improve pain.
- Monitor drug side effects like weight gain, secondary fatigue, daytime sedation, cognitive dysfunction and sleep disturbance.
- Select interventions aimed at primary underlying mechanisms. This will allow the use of fewer drugs to address multiple symptoms with minimal side effects.
- When you move into long-term management, simplify medications and prescribe the lowest effective doses. Shift gradually to more nonpharmacological interventions whenever effective. Taper or reduce medications when possible, and discontinue them when no longer needed.
- Physicians need to monitor their patients use of supplements. For instance, patients who take Florinef for orthostatic intolerance probably shouldn't also take raw licorice, which works like Florinef and lowers potassium levels. Physicians should monitor potassium levels in such patients and check for hypokalemia.
- Physicians can help patients understand that the inappropriate use of supplements can not only be detrimental to their health, but to their wallet. Patients desperate for relief can sometimes spend hundreds of dollars a year on supplements and receive marginal benefits.

pathophysiology is just too complicated to make it amenable to primary care. I've come to believe that the better way to manage this illness is regional Centers for Excellence, where a team of specialists in chronic fatigue syndrome can diagnose, subtype, measure prognostic indicators and develop therapeutic recommendations that patients can then take to their primary care physicians."

The other clinicians on our panel agree that Centers for Excellence are needed. As Bell emphatically states, "Most physicians are not CFS experts and they need a place to send patients and know they will be taken care of properly. This concept works extremely well for other illnesses that have Centers for Excellence, and it would have an enormous impact on CFS care."

### No magic pill

While Peterson's advocacy on this issue has been instrumental in the Nevada legislature's funding of a CFS and cancer Center for Excellence in

that state (see story on page 6), diagnosis and treatment of CFS in a primary care setting is still the norm.

Although there are a number of drug interventions and other therapies that are useful in CFS care, there's no single treatment protocol that really fixes the illness at its core. Pharmacological approaches have failed to resolve CFS. As Stephen Straus, MD, says in a 2004 *JAMA* article, "no drugs prove to ameliorate the core feature of CFS: physical and mental fatigue so profound and oppressive that the term *fatigue* seems inadequate at times to describe it."

Although patients long for a pill or "magic bullet" to cure their CFS, current best practices for clinical care of CFS include a combination of symptom management, coping strategies, activity management/pacing and exercise therapies. In fact, the physicians on our panel encourage patients to quit looking for the magic bullet that will cure them and focus instead on integrative and proactive strategies to manage the illness.

## Coping strategies

The importance of coping strategies usually gets tagged on to the end of discussions of how to treat CFS. This may be because physicians feel more comfortable talking about symptom control and pain or sleep medications than they do about coping techniques. The patients' own desire to have a quick fix instead of embracing harder-to-accomplish lifestyle changes, also contributes to this oversight.

With CFS, however, learning to cope with the illness is one of the best strategies for treatment. "If we could deal with the physical aspects of CFS, then the emotional aspects wouldn't be a problem," says Bell. "But because treatment of the physical symptoms is so unsatisfactory, treating the emotional aspects in terms of coping becomes much more important."

"I do believe that symptoms such as sleep, mood and pain should be controlled, but even more importantly, the patient has to fashion a whole lifestyle change," advises Levine. "Patients who have achieved an acceptance of the illness and who surround themselves with friends and family mem-

bers who are generally supportive seem to fare better overall. Avoiding anger and stress and learning how to handle negative emotions may also be helpful."

Pocinki agrees. "It's quite important for patients to be proactive in their care. Patients who sit around feeling sorry for themselves or waiting for someone to find a magic-bullet cure don't improve as a rule. Patients who continue to look for new treatments, stay optimistic about recovery and try to find new ways to cope with their illness tend to have a more positive outlook and a better prognosis."

That's not to say that patients aren't justified in their emotional response to such a devastating illness. Dr. Renee Taylor, a licensed clinical psychologist and professor at the University of Illinois at Chicago, explains: "Patients are justified in their feelings of anger about the imposed changes and losses of CFS. Once they recognize their feelings of anger, I validate and even encourage them because I see anger, when expressed appropriately, as a positive and healthy emotive state."

Taylor continues, "Most forms of anger emerge from a fundamental experience of loss. Losses with CFS are profound, multifaceted and not limited to social, economic and functional losses. Anger resulting from the CFS experience can also stem from stigmatization and social oppression. Having to confront negative responses to the illness, particularly from loved ones or health care professionals, can lead to natural feelings of resentment, loss, rejection, anger, and in some cases, rage."

That's why finding health care professionals who believe CFS is real and don't equate it with depression is so important, and may actually qualify as a coping strategy. "A toxic relationship is born when the doctor doesn't believe the patient, or the patient can't trust the doctor," explains

Lapp. "There's no compelling reason to spend time and energy in such a situation. The patient needs to run—not walk—and find another advocate."

Learning to manage the anger, stress, guilt and denial that come with having CFS isn't easy. Clinicians on our panel encourage patients to explore various approaches, including counseling with a psychologist who understands CFS or participation in a support group. Alternative therapies





“Attributing CFS to depression leads to diagnosis anxiety, uncertainty, lack of trust in the physician and an unwarranted delay in proper diagnosis and management. In a study of 11 new patients who consulted me, the diagnosis had been delayed for more than two years, and the patients had spent an average of \$26,000, excluding hospitalization, seeking the correct diagnosis.”

—DR. CHARLES LAPP, HUNTER-HOPKINS CENTER

## Man of Steel

On first impression, **Dan Peterson, MD**, appears quiet and mild-mannered, even self-effacing and detached. It's only on longer acquaintance that you glimpse the steely determination and vast compassion beneath the veneer. That tenacious spirit and depth of compassion has been vital to keep this pioneering CFS physician in the field because the obstacles he's endured would have been too high or too many for someone made of lesser stuff.

Peterson, together with Dr. Paul Cheney, was among the first clinicians to identify CFS in the United States. In 1984 in their Incline Village, Nevada, internal medicine practice, a few cases of what they initially thought was a persistent viral infection became 150 cases of something that lingered, zapping patients with a host of disabling symptoms. This cluster of cases garnered attention not only from the media, who speculated about an epidemic, but also from disease detectives from the CDC, who descended on Incline Village in 1985. The CDC's initial dismissive reaction to the illness, and the careless and insensitive coverage of CFS by some media, contributed to a cultural response to this illness that became the first major obstacle to effectively helping CFS patients

In Peterson's opinion, that cultural response to an enigmatic illness has left a legacy that patients, clinicians and researchers interested in CFS are still dealing with today. “Among patients and their families, and researchers at the CDC and in the field, there is much greater recognition that CFS is real and worthy of attention. The legal system has come a long way too. I find that more disability judges are familiar with CFS and willing to grant disability to patients. But I'm very frustrated that there hasn't been more improvement in the general public's response to CFS.” By far, however, Peterson believes the group that's least receptive is health care professionals. “Physicians are still incredibly resistant to treating CFS, or taking on patients. I still hear a lot of disdain from other physicians.”

Peterson believes the underlying reasons are far more complex than the fact that many health care providers still don't acknowledge CFS is a real biological illness. “Even physicians who do believe CFS is real don't want to handle this patient population. They become frustrated with not being able to help patients enough and so they disconnect from patients and this illness.” Added to a lack of professional fulfillment are the realities of managed care. “Chronic fatigue syndrome is not very amenable to primary care and the way medicine is practiced today. The average time a physician can spend with a patient has decreased to seven minutes, and with this disease that simply isn't enough. CFS is too complex and doesn't fit the cookbook type of protocols or algorithms for managed care that characterize clinical medicine today.” Thus, financial realities discourage physicians from taking on more than one or two CFS or FM patients. Clinicians can't charge or be reimbursed for the actual amount of time it takes to deal with these patients.

So how does Peterson manage to remain so passionately committed to working with CFS patients in spite of all the obstacles? “I believe in a central truth—that science will eventually triumph. There has been scientific progress in understanding this illness. We do know much more than we knew 20 years ago, and the puzzle pieces are coming together.”

Those two decades have been long ones, however, and in more contemplative moments Peterson sometimes wonders if he has “contributed enough to the field as a whole in 20 years, as opposed to contributing to individual care. What I have done is see individual people and hopefully made the quality of life better for them, but I haven't cured them or been able to contribute as much to clinical research as I'd like.” For the patients in the original 1984 cluster who are still in his care, others who have actually moved to Nevada to be near his office and patients who make annual pilgrimages to see him, the answer is clear. This man of steel, this man of compassion, this CFS pioneer has not wasted his life or his talents. He has dedicated his life to helping patients, and they love him for it.

## A New Definition of Exercise

It's somewhat ironic that for an illness where patients are often diagnosed as deconditioned and characterized as lazy, exercise exacerbates symptoms rather than relieving them. Well-meaning health care professionals often recommend aerobic exercise as a cure-all for the symptoms of CFS without fully understanding the potential consequences of their prescriptions. As anyone with CFS who has attempted to "get fit" using traditional approaches to exercise knows, the results can be devastating.

Contrary to the popular mantra "no pain, no gain," the reality of exercise for many CFS patients is "no gain, much pain!"

The solution perhaps lies in understanding how the body uses energy. It's our experience that if physical activity is to become a positive in the lives of CFS patients, they must forget the traditional approaches to training that so often fail. It's not how much effort you put out, but rather how well you recover from the effort that is important. Patients need to recognize that it's okay to exercise for a very short time and rest. The activity should be restorative, or analeptic, serving to relieve, not exacerbate, symptoms. Redefining exercise in this way acknowledges that a cookie-cutter approach to exercise therapy for CFS won't work because one size does not fit all.

**1** A typical analeptic exercise program progresses through four stages. Patients should begin with stretching and strengthening exercises. These might include focused breathing exercises, step-ups, wall push-ups, modified chair dips and toe raises. Stretching can be done between strengthening exercises. An exercise progression goal would be increasing from one set of four repetitions to two sets of eight.

**2** For stage two, as strength improves, resistance in the form of Thera-Bands or light weights can be added to the workout. Over time patients should, as one expressed it, "feel stronger, more flexible and able to get around better."

**3** Stage three of the program comprises dose-controlled interval training—exercising large muscle groups for a specific length of time interspersed with periods of rest. This could involve walking up and down stairs with a chair situated on the landing to permit resting between intervals. Success of this stage is dependent on patients learning to monitor heart rate so they avoid pushing too hard and triggering relapse. A functional goal would be for the patient to engage in activities of daily living without precipitating postexertional malaise.

**4** Finally comes the maintenance stage. To ensure patients transition from chronic fatigue to chronic exercise, it's important that they perceive improvements in functionality. Setting realistic, functional goals and keeping an activity diary can provide motivation. Positive feedback and support from family, friends and care providers is essential to success.



By Christopher Snell, PhD, University of the Pacific; Staci Stevens, MA, Workwell Foundation; and J. Mark VanNess, PhD, University of the Pacific;

such as massage or healing touch; deep breathing and muscle relaxation techniques; and movement therapies like stretching, yoga, tai chi and qigong can also be beneficial.

One of the most controversial treatments for CFS is cognitive behavioral therapy (CBT). It can, however, help patients cope with the illness and manage symptoms. Some patients are fiercely opposed to it because they believe it suggests that if they'd just change their behavior or their attitudes about the illness, they would get better, supporting the notion that CFS is caused or perpetuated by psychological rather than physiological factors. This opposition has been strengthened by the British approach to CBT.

"I don't take the British point of view that CBT is the once thing you can do to effectively treat CFS" says Klimas. "But it is a tool that helps some patients. I include some sort of CBT therapy with all my patients to help them cope with the illness, develop strategies to manage symptoms, create a support system and have the best quality of life possible within the confines of the illness. CBT can definitely help manage fatigue symptoms, and I have some patients who say it's the best thing I've ever done to help them. Others experience less benefit, but I hate to see patients categorically refuse to try CBT because it can help some of them achieve a better quality of life."

Lapp agrees. "In my opinion CBT is widely but unfairly maligned because of the British approach, which presumes that CFS has no organic basis, and is therefore contradictory to most patients' perspectives and current science. This type of CBT assumes somatic symptoms are perpetuated by errant illness beliefs and maladaptive coping."

Bell, who cautions against viewing CBT as a miracle treatment, looks at it as a kind of coping mechanism. "It won't suddenly make patients better, but it can help them utilize their abilities and skills in a way that improves their mental outlook and functionality. I use CBT on every patient I see. I don't refer them to outside CBT therapy."

Peterson says he's "not convinced of the efficacy of CBT, but it may be because I don't have a good practitioner in my area. It deserves to be tested, but sending patients to therapists who don't understand CFS is not something I'd comfortably do."

## Activity levels and exercise

The clinicians on our panel agree that learning to manage activity levels is key to managing the illness itself. By attempting to increase activity on their good days, patients often become trapped in a push-crash cycle. Unfortunately, the desire to avoid the postexertional malaise and profound mental and physical fatigue that are hallmarks of this cycle often causes patients to avoid activity and exercise altogether. This avoidance results in serious deconditioning and can actually exacerbate other symptoms. Learning how to pace themselves, avoid the push-crash cycle and manage activity is critical.

“Exercise is frequently misunderstood by physicians and patients alike,” says Lapp. Whenever I mention the e-word, people immediately think of joining a gym or a cardio program. Exercise is one of the few treatments that predictably improves CFS, but it must be undertaken by ‘starting low and going slow.’ Many patients can exercise for remarkably short periods, just 3-5 minutes at a time, without risking a relapse. We have found that interval activity is best—repetitions consisting of 3-5 minutes of exertion followed by 5 minutes of rest. Patients can increase their exercise time by one minute every 7-10 days, but we discourage them to do no more than 10 minutes at a time.”

This approach is similar to the techniques used by Staci Stevens, who, according to Bell, has the “best handle on activity and exercise for CFS patients than anyone else in the country.” (See boxed story on page 52.)

“I refer as many of my patients as possible to Staci Stevens for exercise therapy,” agrees Peterson. “She gives them labor-intensive, individualized care, and I get very positive feedback from patients.”

But for patients who don’t have access to Stevens or exercise therapists with similar approaches, there are other exercise regimes that can be facilitated by their primary care physician. Klimas believes exercise is critical, and she prescribes a four-pronged program. First, she suggests a good stretching regime or yoga. Next, she encourages patients to focus on modest strength-building exercises. “Your muscle mass sets your metabolic rate, and lots of CFS patients have a very low metabolic rate and have gained weight, so building muscle mass is important. This doesn’t mean bench-pressing 200 pounds. It can be as simple as lifting a

## On the Frontier

### Controversial Treatments Show Results

Two treatments that are controversial among some patient groups may actually represent real advances in the treatment of CFS. Part of the problem is that they’re poorly understood. The following overview may help demystify these often demonized therapies, which research suggests can help a majority of patients.

**COGNITIVE BEHAVIORAL THERAPY.** Cognitive behavioral therapy (CBT) is about examining how your thoughts, feelings, actions and symptoms relate to one another. This enables you to understand the link between them, and then try out new ways of breaking those links. A cognitive behavioral therapist helps you to understand your illness and change the way you manage it. In between sessions you try out new ways of managing your CFS, with mutual feedback on successes and failures at the next session. CBT starts with you setting a baseline of activity and then gradually increasing what you do in order to reverse the cycle of either inactivity or “boom and bust.” Other CBT techniques include mutual problem solving of stress and sleep quality improvement. The aim of this therapy is to help you manage your symptoms more effectively and to do more.

**GRADED EXERCISE THERAPY.** Graded exercise therapy is all about gradually increasing your physical activity in order to reverse the inactivity and physical deconditioning associated with CFS. Usually, you see a physiotherapist who helps you work out a basic activity routine that you can cope with even on a bad day. Then together you plan to gradually increase the amount of physical activity or exercise you do. The gradual increase takes into account your symptoms, fitness and current activity levels. The aim of this therapy is to help you do more and feel better, since we know that exercise/activity helps to reverse many of the physical consequences of CFS.

**DO THESE TREATMENTS WORK?** Since 1996 there have been eight published studies of these two treatments, compared to various other treatments. These studies were reviewed by four independent groups of scientists, who all concluded that active rehabilitation with CBT and GET are the most promising of all treatments in adult patients able to attend hospital clinics. Approximately 6 out of 10 patients rated themselves as much better after either CBT or GET compared to before treatment, which was significantly higher than the proportion improving with the comparison treatments. About a quarter of patients were rated as recovered from CFS after utilizing CBT, a rate maintained after five years. This year a further study showed that CBT was also helpful in treating adolescents with CFS. No study has shown any pattern of harm caused by either treatment.



By Professor Peter D. White, Professor of Psychological Medicine, Barts and the London Queen Mary School of Medicine and Dentistry, St. Bartholomew’s Hospital, London, UK

## Scientist and Crusader.

Dr. Lucinda Bateman is a crusader, although she would never call herself one. Dedicated physician, vocal advocate, gifted teacher—she might agree to these designations. But crusader, no. Instead, she thinks of herself as a scientist and healer, firmly rooted in academic discipline and empirical reasoning. In fact, she is both scientist and crusader.

Bateman has spent the last 15 years working with patients who have CFS or fibromyalgia (FM). Her keen interest in these diseases began in the mid-1980s when her sister, Shauna Bateman Horne, became ill with what would eventually be diagnosed as CFS. Dr. Bateman, a medical student at Johns Hopkins Medical School at the time, watched her happy and healthy sister suffer with a series of illnesses that exacted a silent and permanent toll.

When Bateman started a private group practice in Salt Lake City in 1991, physicians across the area referred their CFS and FM patients to her. What began as an effort to help her sister took on much broader implications as she worked with scores of patients who had ill-defined chronic illnesses. She studied the research, attended conferences and networked with other physicians treating these diseases. But it wasn't enough. In 2000 she left her practice to focus exclusively on CFS and FM, opening the Fatigue Consultation Clinic in Salt Lake City.

"My mission is to change the way these diseases are treated in my sphere of influence in Utah," she says. "I come from a disciplined academic background. Plus I have experience first with my sister and now with my extensive clinical practice. So I have my feet in both worlds. I think my job is to bring the information that's sound, good scientific information to the attention of academic institutions and health care providers in Utah so they will become more interested and involved with these diseases."

That mission became much more personal in May 2001 when her beloved sister died of complications related to non-Hodgkin's lymphoma. "I believe her long battle with CFS may have predisposed her to the development of this malignancy," Dr. Bateman says.

At her outpatient clinic, Dr. Bateman has designed a thorough and methodical three- to four-hour workup of new patients. Her goal is not to treat large numbers of patients, but to "move patients to a better level of function." Still, she has seen more than 800 new patients with CFS or FM since the clinic opened in 2000.

Outside of her clinical practice, Dr. Bateman is also the co-founder and executive director of OFFER, the Organization for Fatigue and Fibromyalgia Education and Research. Her brainchild, this nonprofit organization was started in 2001 to spearhead research, education and advocacy efforts.

Dr. Bateman's work has brought her accolades over the years. She has been named Teacher of the Year four times for her work in the Utah physician assistant's program. And in 2000 she was one of only three Utah internists selected by her peers to be named in Top Doctors, a national publication. But it's not the awards that keep her motivated. It's the drive to change the way CFS and FM are diagnosed, treated and researched. "There's a huge difference in the way these diseases are regarded by physicians and the public today compared to when my sister was first diagnosed with CFS. But we still have a long way to go. The battle isn't over."

You can bet Dr. Cindy Bateman—scientist and crusader—will be on the front lines of that battle.

can of soup and gradually increasing the number of reps." The third focus is on strengthening the central core muscles. "If you have a stronger abdominal wall, you don't pool as much blood in your vena cava and abdomen, so central core strengthening helps." She encourages patients to buy a Pilates tape and do 5-10 minutes, then later in the day do another 5-10 minutes. The fourth prong of her exercise program is aerobic exercise. While some patients are scared of aerobic exercise, Klimas has found that patients tolerate it better if they do it for 5 minutes, then rest for 5. "Upright aerobic exercise can be done in little chunks. For patients who don't tolerate an upright position, a recumbent bicycle is a possibility."

Although exercise won't cure CFS, and in some cases offers only marginal or moderate improvement, many patients report symptom relief, particularly a reduction in muscle and joint soreness and improved cognitive functioning. "I tell patients that

small amounts of exercise can improve mood, sleep and pain," says Levine.

Just as important is the role exercise plays in preventing deconditioning. "Patients who have curtailed all physical activity will continue to lose muscle tone and just tire that much more easily when they try to do anything," says Pocinki. While he's not convinced exercise is a miracle therapy, "without it, recovery doesn't happen."

Klimas agrees. "Studies have shown that deconditioning itself leads to CFS-like symptoms. Even

if a profoundly deconditioned patient suddenly recovered from the illness itself, the symptoms would remain, and the patient would still have low muscle mass and high fat mass and wouldn't feel any better."

## Managing sleep

When it comes to symptom management, clinicians agree that they treat sleep first. That's not only because 70-95% of CFS patients experience sleep dysfunction, but because sleep problems exacerbate other CFS symptoms. (See article beginning on page 32.)

"I start with sleep," says Klimas, "because if you don't manage the sleep right, you don't get far. It's



difficult to untangle the threads of the illness until sleep dysfunction is addressed.”

Sleep is hard to address effectively because many patients don't respond to conventional treatments or develop side effects from drug interventions. “More often than not, I refer them to a sleep specialist who usually orders an overnight sleep study,” says Levine.

Klimas also prescribes sleep studies because she finds sleep management problematic with CFS patients. “However,” she cautions, “I recommend that patients see a neurologist rather than a pulmonologist for a sleep study because pulmonologists are usually only looking for sleep apnea, and study results don't show the kind of sleep dysfunction CFS patients have. Neurologists come from a more global perspective.”

Our panelists start with recommendations for good sleep hygiene, encouraging patients to establish a regular bedtime routine; avoid napping during the day; control noise, light and temperature in the bedroom; and avoid caffeine, alcohol and tobacco. Gentle exercise and stretching earlier in the day, not close to bedtime, can also improve sleep. Relaxation techniques like deep breathing and massage closer to bedtime may also be of benefit.

Although our panelists were open to the use of herbal remedies like melatonin and over-the-counter drugs like benedryl and Tylenol PM, these usually don't provide enough relief. Pocinki says, “Most patients need a combination of meds—one for sleep initiation (most often Ambien or Ambien CR), one for sleep maintenance (most often amitriptyline or trazodone) and one for pain (most often a muscle relaxant like Flexeril or a NSAID).”

Lapp says the most successful combination he has found is clonazepam to fall asleep and trazodone to maintain sleep. Tricyclic drugs (such as amitriptyline, doxepin or desipramine) or tetracyclics (such as mirtazapine) can also be of benefit. “We also consider sleep-inducing hypnotic drugs such as Sonata, Lunestra or Ambien,” Lapp says. “We try to avoid benzodiazepine sedative-hypnotics such as lorazepam and diazepam because they tend to disrupt normal sleep patterns and have a potential for habituation. The exception would be Klonopin, which is long-acting and also treats restless legs and myoclonic jerking.”

Levine, who often starts with low doses of liquid Sinequan, will also prescribe Klonopin in low doses if the patient is still having difficulty falling asleep.

Then she “might try low-dose trazodone, amitriptyline or norpramin. Occasionally, I'll use neurontin or cyclobenzaprine for sleep. And for patients who are deficient in growth hormone, replacing this hormone can improve sleep patterns.”

## ONLINE BONUS!

Read more about treatment online. You'll find a comprehensive review of pharmacological treatments for CFS, including prescription drugs, nutritional supplements and herbal remedies. Writer Loretta Spotilla, PhD, also reports on research studies that have been done on these interventions. Go to <http://www.cfids.org/special/pharma.asp>.

## Managing cognitive problems

After sleep, there is less certainty about which symptom to tackle next, and many clinicians say it depends on which one is causing the most difficulty. “It's all about treating a symptom at a time,” says Peterson. “I have patients prioritize their symptoms to see which symptom is most troublesome or most disabling, and then we work on that together.”

For many patients that symptom is cognitive dysfunction. Unfortunately, cognitive dysfunction is probably the hardest CFS symptom to treat, and some clinicians on our panel readily admit they have little success in ameliorating cognitive difficulties.

Coping and adaptive techniques, which can be thought of as an informal kind of cognitive behavioral therapy, are usually suggested. “I encourage CFS and FM patients to have three items available at all times—a notepad, calculator and calendar, or an organizer that combines these aids,” Lapp says. “Patients can also develop helpful habits such as putting keys in the same place or parking in handicap spaces so they can remember where they parked.”

Patients are also encouraged to try cognitive remedial training. For instance, Lapp encourages patients to stimulate the mind with jigsaw and crossword puzzles, word games, card games, board games and computer games. “Perhaps the most successful treatment for cognitive dysfunction is brain wave biofeedback. In this therapy, specialists train the brain to speed up or to shift thinking centers to more appropriate areas of the brain. The technique,

Insert drug chart here

however, is costly, time-consuming and not widely available.” (For more information, see Dr. Myra Preston’s website at [www.siberimaging.com](http://www.siberimaging.com).)

“Your brain is a work in progress, and you can teach your brain to think on new tracks,” adds Klimas. “Research shows that CFS patients have difficulty concentrating and with short-term memory, and that they may have to recruit more areas of the brain to complete a task. Even playing a simple game of Concentration can lay down new tracks for short-term memory.”

Klimas also notes, “Some therapies that make the most sense for cognitive difficulties aren’t directed to the brain. Many CFS patients have autonomic dysfunction. Orthostatic problems can contribute to the brain fog, and treating these can improve cognitive function. Treatments that improve autonomic dysfunction improve brain perfusion, or blood flow to the brain.”

Treatments for orthostatic intolerance include volume expansion, which essentially means increasing fluid volume by drinking fluids and increasing salt intake. If simple volume expansion doesn’t improve symptoms, Florinef (fludrocortisone) is often prescribed. If there’s still no significant improvement, “a beta blocker might be considered for patients without serious allergies,” Klimas adds. “I’ve also found Midodrine to be very helpful.”

Other drug interventions for cognitive problems include stimulants. “Modafinil, or Provigil, is occasionally very helpful, so it’s almost always worth trying,” says Pocinki. “But I’m wary of using stronger stimulants since they can precipitate the dreaded push-crash cycle. As one patient memorably put it, ‘Taking stimulants is like borrowing energy you don’t really have. You feel better while you’re on it, but when it wears off, you crash.’”

Bateman also finds stimulants helpful for fatigue and cognition, but advises that they “should be used cautiously because of the impact on sleep, anxiety and the tendency to overexert instead of pace activity appropriately.” Most clinicians prefer Provigil due to safety and effectiveness, but Adderall and Ritalin are also helpful and less expensive.

“This is a unique situation in medicine. Patients know more about CFS than most doctors around the country do. That makes it extremely important for patients to be proactive in their own care.”

—DR. DAVID BELL, PRIMARY CARE PEDIATRICS



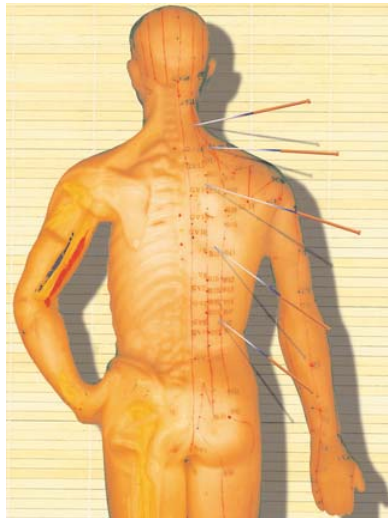
## Managing pain

There are a few nondrug treatments for helping CFS patients manage pain. For instance, stretching and movement therapies can be useful for managing the pain of CFS and FM and are often recommended. “Heat, toning exercises and acupuncture can also help reduce pain without medication,” says Pocinki. In fact, acupuncture seems to be the most common nondrug intervention prescribed by the physicians on our panel who have access to a qualified practitioner to refer patients to for expert care.

Drug therapy, however, is usually needed to control pain. Pocinki finds that many CFS patients are resistant to taking pain medications and deny how serious their pain is. “I have to explain that the pain they’ve learned to live with is a major factor in their fatigue, poor sleep, even their depression. Even if daily medication only reduces their pain by 10-20%, this can have a significant effect on their energy, mood, sleep and overall well-being.”

Several clinicians on our panel have been trying Lyrica with some success and few side effects. They also report that some patients do well on Ultram or Ultracet, which has been shown to reduce both pain and tenderpoints when used regularly. Cymbalta, which can sometimes replace a low-dose SSRI, can be useful not only in reducing pain but in improving mood. Anticonvulsant drugs such as Neurontin can also be effective in pain management.

Although many physicians shy away from opiates, Lapp believes “opiates should be considered when pain has a significant impact on lifestyle and



function, conservative methods have proven inadequate and pain is moderate to severe.” He continues, “Large studies have demonstrated that the risk of addiction is less than 4 per 12,000 cases, and mostly limited to those with a past history of substance abuse.”

### Managing immune dysfunction

Although much of the research to date on pathophysiology deals with immune dysfunction, it hasn't yet led to widely used immunotherapies. There is some controversy about using SSRIs as immunomodulators, and most clinicians recommend limiting their use to nondepressed CFS patients.



Phase 2 trials for Ampligen, an immune-enhancing drug, have been completed, but results haven't been published yet. And while it shows promise for CFS treatment, it's very expensive.

Isoprinosine is a “promising and exciting drug that's well tolerated, has low toxicity and isn't terribly expensive,” reports Klimas. Results of a Phase 2 study in Canada were recently published, and a 2006 trial in the United States has recently been announced by Newport Pharmaceuticals.

Levine is currently evaluating ReVia (naltrexone), a blocker of endorphins, which may boost natural killer cell activity when administered in low doses.

### Incorporating alternative therapies

Because traditional drug and nondrug therapies fail to resolve CFS, and sometimes don't significantly improve quality of life and function, patients usually explore complementary and alternative therapies. Physicians on our panel don't discourage this exploration and even routinely prescribe some of these therapies.

Acupuncture is often recommended for pain, chronic headaches and energy. Finding an experienced and skillful practitioner, however, is essential, and finding one who understands CFS is especially helpful.

Movement and stress-reducing therapies are also commonly prescribed. Among these are yoga, tai chi, qigong, massage therapy and deep breathing. “Treatments that require constant supervision are less likely to be performed consistently, so they'll only give temporary relief,” says Levine. “I think stretching exercises and yoga poses can give the patients more lasting relief since patients can perform the techniques on their own once they are taught to do them properly.”

Hydrotherapy is another complementary technique endorsed by our panel. “Hydrotherapy is clearly one of the most beneficial and enjoyable activities for CFS and FM patients,” Lapp believes. “The buoyancy provided by soaking in a pool is particularly helpful for those who have foot, knee or hip problems. Water therapy simultaneously provides exercise, improves balance, treats orthostatic intolerance and reduces fibropain. Many of my patients refer to water therapy as liquid gold.”

There is some evidence that CFS and FM patients are prone to nutritional deficiencies. One study published in 2000 suggests patients are low in the B vitamins, vitamin C, magnesium, sodium, zinc, L-tryptophan, L-carnitine, coenzyme Q10 and essential fatty acids. Nutritional supplements may help address these deficits and provide marginal improvement, and serious adverse reactions are rare when patients follow dosage instructions.

“Just because 400 milligrams is good doesn't mean 800 milligrams will be better,” Klimas cautions. “For instance, megadoses of vitamin E can increase your risk for cardiovascular disease. Patients who are taking a multivitamin, a vitamin E capsule and fish oil capsules in which vitamin E is often a hidden component can accidentally ingest far more than the 400 milligrams that is the maximum safe daily dose.”

While there have been very few clinical trials to support the use of particular supplements, two studies suggest that oral NADH (nicotinamide adenine dinucleotide), which is important for cellular production of energy, may be helpful for treating CFS. Methylcobalamin, a form of vitamin B-12, has also been studied and is among the supplements that have some support from clinicians. Essential fatty

acids like fish oil, evening primrose oil and flaxseed oil also get a thumbs-up from our panel. Other generally accepted supplements include coenzyme Q10 for antioxidant properties, L-carnitine for energy and acetyl-L-carnitine for memory.

Levine, who uses many nutritional supplements in her practice, says she often prescribes hydroxycobalamin and IM magnesium sulfate. The supplement Neem, an extract from the tree *Azadirachta indica*, has been shown to have activity against HHV-6 in vitro. Levine has tried this drug with some success.

Bateman, who isn't philosophically opposed to supplements, nevertheless believes they can't take the place of good diet and nutrition. "I advise my CFS and FM patients to eat a good diet, avoid excessive sugar, caffeine and alcohol, and try not to gain weight while ill." She doesn't feel that supplements or herbal remedies are more helpful than conventional medicine, but she asks her patients to try only one new thing at a time and to be very self-observant in order to track potential effects of the new therapy.

Because they aren't especially knowledgeable about herbal remedies, the clinicians on our panel declined to offer recommendations for efficacious herbal treatments. They advised patients to avoid comfrey, ephedra, kava, germander, skullcap, chaparral, aristolochic acid, bitter orange, yohimbe and any other supplements that are potentially dangerous. Reliable information on supplements and herbal remedies can be found at Memorial Sloan-Kettering Cancer Center's website at [www.mskcc.org/mskcc/html/11570.cfm](http://www.mskcc.org/mskcc/html/11570.cfm).

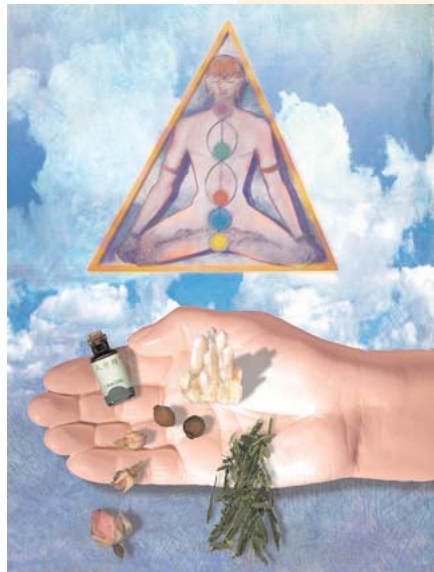
## Striving for health

It would be wrong to conclude that if patients just work hard enough to find the right combination of all the treatment strategies discussed above, then they'll get better, or at least substantially improve. The bitter, unpalatable reality is that patients can be proactive, they can have a good attitude, they can try various drug and nondrug interventions, and they can still remain ill, even profoundly disabled.

Results are uneven. One patient can achieve a

## A New Model for Combining Western Medicine and Chinese Herbal Therapy

Insert Gilbert article



much greater level of functionality with acupuncture, while the next sees no benefit with this treatment, even from the same practitioner. One patient may see significant improvement in quality of life through symptom management, but the next will not. In the face of so much uncertainty and uneven results, the best course is for CFS patients to find a physician who is knowledgeable about the illness, or willing to learn, and who can become an effective partner in managing this illness. It's up to patients to take a leading role in their own health care and do everything possible to increase their chance for the best therapeutic outcome possible.