



Finding ways to stay in the workforce can be challenging for CFIDS sufferers. In this article, a well-known expert helps guide you through the process of **securing workplace accommodations**.

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# Staying on the Job

Having a hidden chronic illness such as CFIDS is stressful by itself, but when combined with the normal stress of a job, you can begin to feel overwhelmed. The state of the current job market, along with the possibility of new layoffs, can leave you feeling like you have absolutely no control over your life. You worry about keeping your job and being able to perform all the tasks that are a part of it. The more you worry, the more stress you experience, and the more the stress impacts your ability to work. It can become an endless cycle, taking its toll on your physical and emotional state. But there *is* something you can do about it.

“Playing the Hand You’re Dealt,” the first article in this series on working with CFIDS (see spring 2004 *Chronicle*), considered the pros and cons of informing your employer about your illness, so that topic won’t be addressed again here. However, that decision will dictate what you do next. In this article I’ll cover ways to help you do your job without revealing your illness, as well as accommodations you can request under the Job Accommodation Network (JAN) if you’re ready to tell your employer about having CFIDS.

## Putting your own accommodations into practice

When you have CFIDS and you want—or need—to keep working, you must decide how to cope with it in the workplace. It’s up to you to take charge of as much of your life and health as possible. You must actively strive to be *proactive*, rather than just being *reactive* to your illness. Because you know your personal situation best, you’ll probably be able to come up with some solutions on your own for accommodating your limitations.

You may have already done things to help in the workplace without even thinking about it. Perhaps you make lists or write yourself notes to help you remember phone numbers, appointments, project due dates and infrequent, but important, tasks. When making those notes, you may already be prioritizing your job tasks by putting the most important first.

Take a conscious, realistic look at the limitations you’re now facing. The most



common symptoms of CFIDS are fatigue, cognitive difficulties, muscle or joint pain, headaches, and sensitivity to light, noise, medications and temperatures. Whether depression and anxiety are a part of CFIDS or a result of it, you may have to cope with these conditions as well. What are your major limitations? How do they impact your work life? How can you compensate for these limitations? How can you perform all the minute details you once took for granted? Asking yourself these questions may sound simplistic, but it's an important step in developing coping mechanisms that can lead to the creation of accommodations you can put in place without your employer's involvement.

Let's look at some of the physical limitations a PWC might face and what kind of accommodations might help you perform your job. Many individuals with CFIDS, as well as those with fibromyalgia, often have difficulty concentrating, are easily distracted and have trouble remembering information on a short-term basis. What can you do to compensate for these problems?

*Celia worked as a secretary/receptionist for a mid-sized firm. She found herself transposing telephone numbers and misplacing important papers on her desk, which rivaled that of the cartoon character Shoe. She was easily distracted from tasks and lost time in picking up where she left off. She knew if she didn't do something soon, she could lose her job.*

*Her first step was to obtain a written copy of a detailed job description, which she then kept handy. She came in on a Saturday and organized her desk and work area, setting it up so she could be more efficient. She set up a tickler file ranking her tasks by importance and subject. While she couldn't con-*

*trol other workers in her office, she did try to minimize the distractions as much as possible. She cleared it with her supervisor to switch her telephone to voice mail to prevent phone interruptions and then returned calls only at set times.*

*She made a point to take frequent breaks away from her tasks, even if it was only to direct her attention away for a few minutes. Although the cost was a bit high for her, she bought an electronic organizer, which stored all the information that was so much a part of her job, and which had an alarm clock to remind her to take a break. She knew there would still be times when rush work and emergencies disrupted her schedule, but it was easier to return to it once the emergency was resolved.*

### JAN accommodations

The Job Accommodation Network (JAN) has been providing information on accommodations since 1983 to employers, government agencies, nonprofit organizations, rehabilitation specialists and individuals. This information is provided free and can be obtained online, via a toll-free phone number or with on-site consultants. JAN was designed to help facilitate hiring and retraining people with disabilities, as well as to help retain or promote these individuals by providing accommodation information.

Anyone can contact JAN for a confidential consultation. When the Americans with Disabilities Act (ADA) was first passed, most requests for JAN services came from employers who wanted to ensure they were conforming to the new guidelines. However, in recent years many individuals with so-called hidden disabilities have begun to contact the network, hoping to find ways to keep working.

Accommodations are defined by

## HOW IT WORKS

**The Job Accommodation Network (JAN) is the most comprehensive resource for job accommodations available. The network provides assistance to employers, rehabilitation professionals and persons with disabilities.**

**JAN has established a uniform job accommodation process to evaluate what accommodations or modifications an individual needs in order to perform the tasks of a specific job. The process looks at existing products or services that could be utilized as accommodations, even exploring the possibility of designing a new product or service if nothing available meets your needs. If JAN professional consultants are unable to find or create a means of enabling you to perform the tasks of your job, the possibility of an alternative job within your company is explored.**

**While JAN can be an invaluable resource, there are no guarantees. Sometimes, despite the efforts made, no accommodation is available and you must look for another job somewhere else, consider self-employment or take some time off work until your condition improves enough to try to work again.**

## CONTACT INFO

**Online information**  
<http://www.jan.wvu.edu>

**Toll-free numbers**  
**1-800-232-9675 or**  
**1-800-526-7234**

**On-site consultations**  
**Call the numbers listed above for information**

## DID YOU KNOW?



**The average cost of JAN accommodations is about \$500, but employers who have provided accommodations have found that the benefits to their business have been in the neighborhood of \$5,000. There are tax credits and other incentives available for employers who choose to make the recommended accommodations.**

JAN as any modification or adjustment to a job or the work environment that will enable a “qualified” employee with a disability to perform the essential job functions. To be qualified, you must have the job skills and knowledge necessary to perform the job.

Let’s look at how some limitations imposed by CFIDS can be handled through JAN. Fatigue, for instance, is a major problem for PWCs, and it can have a negative impact on work attendance and punctuality. There are several possible accommodations in this instance; most of them, however, require you to inform your employer about your chronic illness for permission to use them.

*James, a PWC, had been struggling for months to keep working and finally discussed the situation with his supervisor. He had used all of his sick days and often came in late because it was so hard to get up in the morning. With the permission of his supervisor, he was able to work flexible hours, arriving later in the mornings and scheduling regular rest breaks during the day. He could even work later with the help of the rest breaks. On his worst days, James was allowed to work from home using his notebook computer. The company also purchased an ergonomic, adjustable chair, as well as some less expensive items such as copy holders, electric staplers and hole punches, and a telephone headset to help with fatigue and the muscle and joint pain James experienced.*

Another typical symptom suffered by CFIDS patients is headaches, which can cause havoc in your workday. JAN counselors routinely help PWCs find accommodations that can help.

*Ann, a social worker, often had migraine headaches caused, in part, by extreme light, noise and chemical sensitivities. To help decrease the factors that contributed to the headaches, her employer changed the lighting in her workstation from fluorescent lighting to task lighting, added a glare guard to her computer monitor*

*and installed window blinds to block outside light. A fragrance-free policy was adopted for the facility, and her company added air purification devices. The noise levels were also reduced by providing environmental sound machines and headsets.*

### Act today

Whether you purchase equipment yourself or your employer does, the important point is to find accommodations that will allow you to either keep your current job or find a new one. There is help available, and it doesn’t always have to be expensive. Many times common sense can provide possible solutions to energy-draining tasks. Sometimes the modifications are more extensive, but there are tax credits available to help with the expense, and there are nonprofit organizations that can provide funding. According to JAN, the average cost of accommodations is approximately \$500, but many employers found they received tangible benefits of around \$5,000, not to mention the intangible goodwill generated by their efforts to retain good employees.

What is important is that you as a PWC step up and begin the process of finding some accommodations that will fit your limitations. No one else has more of a vested interest in the accommodations than you do, so it’s up to you to start the ball rolling. The reality is that no cure or effective treatments are available right now, and many PWCs need to work for their own self-esteem, as well as to support their family. Don’t be hesitant to find ways to function better in the workforce. And don’t let inertia keep you suffering when some proactive steps could help your workday be more productive, less painful and less frustrating. ■

*Gayle Backstrom is the author of I’d Rather be Working, When Muscle Pain Won’t Go Away, and The Resource Guide for the Disabled. She has had fibromyalgia since childhood and was recently diagnosed with CFIDS, diabetes and peripheral neuropathy. She has used a wheelchair for the last 3 years and an electric scooter for 10 years before that.*



*Gayle has been a professional writer for more than 35 years and during much of that time, she found unique ways to keep working, often developing accommodations before she was even aware of the term. She lives in Denton, Texas, with a new roommate, who takes care of the more physical tasks so Gayle can continue writing. She also has five cats who bring love and laughter to her life.*