

Work

Strategies and accommodations
can help keep you on the job
after a lupus diagnosis

By Stephanie Watson

It Out

Processing payroll as a finance manager isn't typically a physically taxing job—unless you have lupus and the stiff, painful joints that go with it. “My hands would freeze up, and I couldn't use them,” Autumn Concepcion recalls of the time three years ago when she was first diagnosed. “I couldn't staple things, I couldn't file things, and I couldn't type. My knees would lock up on me, so if I sat for too long, I couldn't get up.” It was a frightening time for Concepcion, who feared she'd lose her job.

Fortunately, her supervisor at Southern Ute Community Action Programs in Ignacio, Colorado, immediately stepped in to help. “I knew she

was in pain, and I knew it was hard for her,” says Chloe Jackson, assistant finance director. “I let her know that we were willing as a department, and as an organization, to be flexible.”

Jackson offered time off for Concepcion's doctor's appointments and new accessories for her desk—including an electric stapler. The human resources department provided an assistant to help with filing and other tasks that proved too difficult. “The whole company did not hesitate to pitch in and help out in whatever way they could,” Concepcion says. “When you go through something that life-changing, and all of a sudden you

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can't do something as simple as type an email, having a network of people behind you at your workplace is huge."

MAKING YOUR JOB ACCOMMODATE YOU

After a lupus diagnosis, if you want to keep working and feel you can still do your job, but you need a few adjustments, you have the right under the Americans with Disabilities Act (ADA) to ask your employer for "reasonable" accommodations. "Accommodations are the steps, equipment, or processes that can be added at work to make sure you can continue working, even though you have a health condition," explains Anne Alcazar, manager of Job Placement Services for Allsup Employment Services Inc., a Social Security-approved employment network. Which accommodations you request will depend on how lupus affects your work abilities.

"For example, if you have trouble getting going early in the morning, you could request a work day that begins later and then work a little later into the evening," Alcazar says. "Another example is asking to use specific equipment or furniture. I worked with one woman and her employer to arrange for her to have a stool by her workstation. Most of her job she could do standing up, but a stool provided her with a way to rest during the work day and remain on the job."

To compensate for fatigue and pain, both



Jonelle Meyer in the Armour Elementary School playground near her home in South Dakota.

common in lupus, you might ask for extra breaks, a closer parking spot, or the option to telecommute. A more ergonomic desk design, along with arm supports and writing aids, can help with joint weakness. When sunlight streaming in through her office windows became an issue for Jonelle Meyer, she asked her company, Wagner Indian Health Service in South Dakota, to add blinds. The company also replaced fluorescent bulbs with low-wattage lights. "Now I want to be here because I don't feel sick and I don't feel fatigued," she says.

Alcazar stresses that accommodation doesn't mean abandoning your job responsibilities. You still have to do the work expected of your position, but "you have some methods that will support you to do the same amount of work as other workers," she says.

HOW TO ASK FOR WORK ACCOMMODATIONS

Approaching your company is often the hardest part of the accommodations process. "It's a very emotional thing to have to ask for help. You have to do it in a very structured way and know what to ask for," says Helena Costakis, a human resources vice president who has lupus.

Start by taking a copy of your job description to your health care provider. Together, figure out which accommodations would help you most, and have your doctor write a note outlining them. "Once you have all your ducks in a row and you know what you need, you can approach your human resources department confidently," Costakis says.

"Often, a face-to-face conversation is the way to begin, and you should make your request in writing," says Anne Alcazar, manager of Job Placement Services for Allsup Employment Services Inc. "Your employer may ask that you complete a form. You also will want to keep a copy for your personal records."

If you haven't yet disclosed your lupus to your company, there's no need to do so—even as you ask for accommodations. "The level of communication that an employee chooses to share is entirely up to them," Costakis says. "Disclose only enough to get the reasonable accommodations to help you be successful."

What if your company refuses your request? Companies can deny your accommodation if they believe it will cause them "undue hardship," meaning it would be too expensive or difficult to implement. Or, they might offer an alternative accommodation they deem just as effective. "This means the employer is trying to work with you, even though it may not be exactly what you wanted," Alcazar says.

If you think your request has been denied unfairly, follow your company's dispute resolution process. Finally, if that doesn't resolve the issue, you can file a complaint with the Equal Employment Opportunity Commission (eoc.gov).

WHERE TO START

You know you need job accommodations, but which ones? “It can seem overwhelming, and you may not know where to begin,” Alcazar says. To learn more about the process, visit the Job Accommodation Network website (askjan.org).

Also, familiarize yourself with the Family and Medical Leave Act (dol.gov/whd/fmla). It allows eligible employees who have worked at least 1,250 hours to take up to 12 weeks off during any 12-month period for care related to their condition.

FINDING JOB SECURITY

It’s understandable to be concerned that requesting accommodations will threaten your job. Your company can’t legally fire you for having a medical condition. And they have good reason to keep you—especially if you’ve been there for several years and know the business, Alcazar says.

Jackson says that the small accommodations the company made for Concepcion were well worth the reward of holding onto a good employee. “When you have employees who are hard-working and loyal, and who come to work every day and want to do their job ... if it means you have to change their schedule a little or tweak their job, then I think it’s the right thing to do,” Jackson says.

“It was huge then, and it’s still huge now, just knowing that if something happens, there’s no fear that I’m going to lose my job,” Concepcion says. “If I’m having a flare-up, people will willingly step up and help me get the things I need to do done. It’s huge job security.”

WHEN IT’S TIME TO MOVE ON

Accommodations aren’t the only option and may not always be the best solution. “While it may be difficult, if you really can’t do the job, you have to assess for yourself whether it’s healthy for you,” says Helena Costakis, who has lupus and is vice president of human resources at a nonprofit in the human services industry.

“I went through this period of stress when I was getting ready to take a big promotion and I had to ask myself, ‘Can I do this physically?’” After considering her limitations, she did take the promotion—but the decision wouldn’t have been right for everyone. “The best thing you can do is not overstress yourself,” she says. “You might want to find something that’s better suited to you and your personal needs.” ■

UNDERSTANDING SOCIAL SECURITY DISABILITY INSURANCE

What if your condition is too disabling for you to work? You may be able to receive Social Security Disability Insurance (SSDI) benefits, but Virginia attorney Sheri R. Abrams warns the process to obtain benefits can be lengthy and is often unsuccessful.

To qualify for SSDI, most people will need to have worked at least 40 quarters—the equivalent of 10 years—and will need to have worked five of the past 10 years. A younger person (someone in their 20s) will not need to have worked as long. Then, the Social Security Administration (SSA) will put you through a rigorous five-step evaluation process:

- 1. Are you working?** “The best situation for getting SSDI is that you’re not working at all,” Abrams says. If you do work, you have to earn less than \$1,090 a month (the amount in 2015) to be considered disabled.
- 2. Is your condition severe?** Will you be unable to work for a year or more, or will your condition lead to your death within that year?
- 3. Is your condition on Social Security’s list of disabling conditions?** Although lupus is listed, many people find their symptoms and limitations don’t match SSA’s description of what it considers disabling for someone who has lupus, Abrams says.
- 4. Are you able to do the same work you did in the past 15 years?**
- 5. Can you do any other kind of work in the national economy?** If you can’t handle your responsibilities as corporate vice president but you

could be a greeter at Walmart, you won’t qualify.

If your case is denied, the next step is a reconsideration process, which also has a high rejection rate. After that, “most people have to go for a hearing in front of a judge,” Abrams says. “That’s where they have the best chance of getting their benefits.” It can take up to 22 months to get a hearing date, during which time you’ll have to stay out of work. And even at a hearing, your chances of getting SSDI are only around 50 percent.



How can you boost those odds? Abrams suggests applying for SSDI as soon as you stop working. Hire an attorney who understands your condition (visit nosscr.org to locate one in your area). And ask your rheumatologist, neurologist, or pain specialist to write a letter explaining why you’re unable to work.

Depending on how long you worked, you can earn up to \$2,633 a month (the amount in 2015). Your children can get additional benefits. “It’s a lifeline for a lot of people,” Abrams says.

Did You Know
ADDITIONAL INFORMATION IS ON OUR WEBSITE: LUPUS.ORG/RESOURCES/EMPLOYMENT-DISABILITY-AND-LEGAL-ISSUES

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LEARN MORE
Social Security Administration’s “Disability Planner: How We Decide If You Are Disabled”: ssa.gov/planners/disability/dqualify5.html#&a0=4