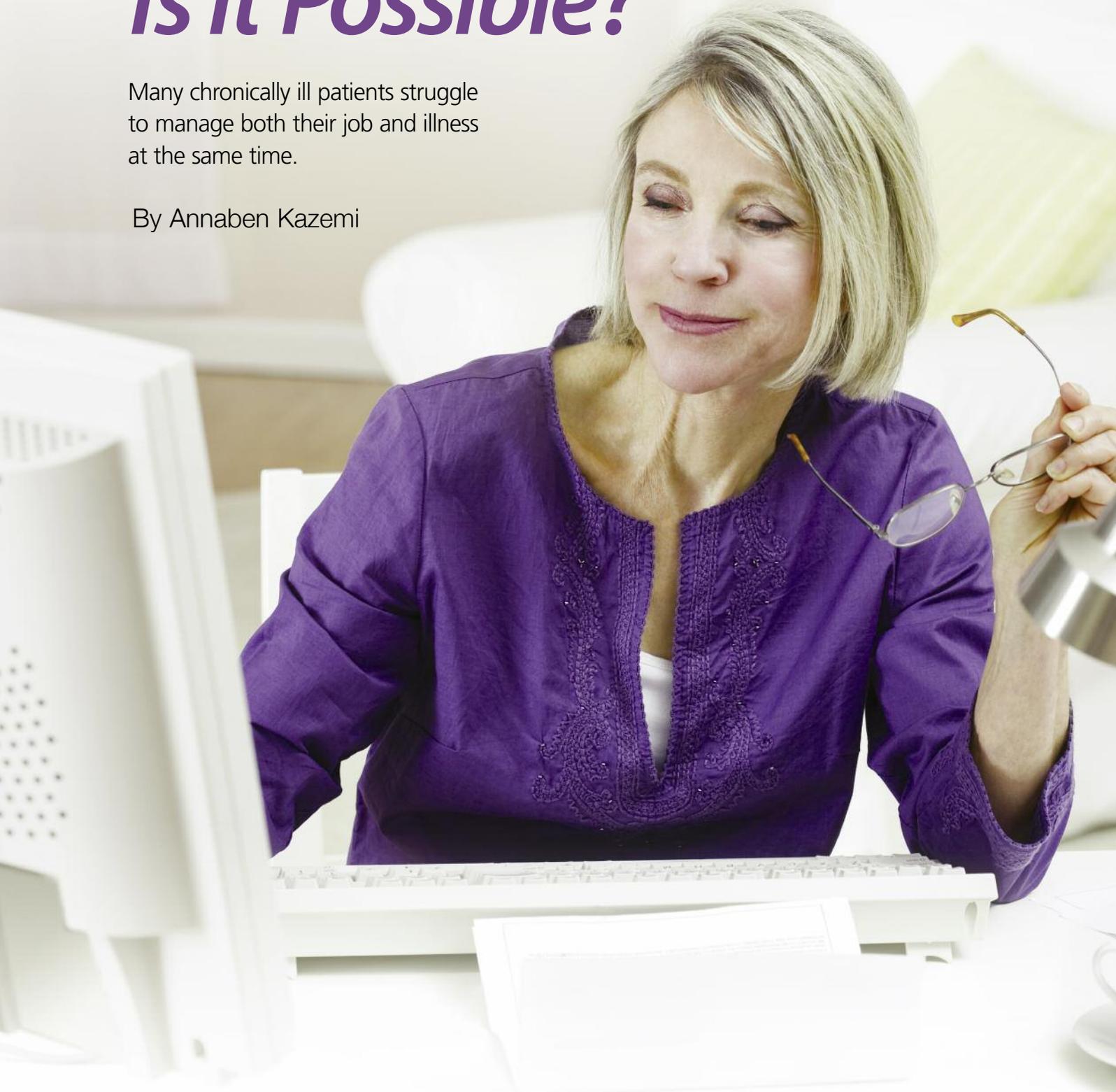


Working While Chronically Ill: *Is It Possible?*

Many chronically ill patients struggle to manage both their job and illness at the same time.

By Annaben Kazemi



Juggling work demands and sick time is never easy, but a chronic illness can make sick days disappear quickly, and bosses can become impatient with the uncertainty. According to the Partnership for Solutions, a national policy research program funded by the Robert Wood Johnson Foundation and based at Johns Hopkins University, more than 133 million Americans now live with at least one chronic health condition, and many live with more than one. By 2030, that figure is expected to grow to more than 171 million. This means an ever-increasing number of Americans face the challenge of managing a chronic illness while working, and many are eventually faced with the difficult decision of having to leave their careers.

Finding a work environment that is accepting and conducive to the demands placed upon individuals with chronic illness is challenging. How to find the right fit depends on each patient's health, skill set and their company's organizational culture. Success is dependent on flexibility and the willingness to make adjustments. In searching for the right fit, patients need to take in account their:

- Current field of work: Is it sustainable and flexible, and can modifications be made?
- Ability: What are the patient's talents, gifts, skills and physical limitations?
- Access to equipment: Are needed tools also available at home; can equipment be modified to meet any physical needs?
- Financial situation: Are funds available if there is change or a setback; can a break in work be absorbed financially?

Once all factors have been taken into consideration, a plan can be put into place. Options patients contemplate most often when building a new plan are telecommuting, modifying the work day or workload, changing careers, working from home and starting a new business.

Telecommuting

One alternative for those coping with ongoing illness is to transition from working in an office to working from home, known as telecommuting. The home work environment can offer chronically ill patients many positives, including a more comfortable setting, privacy and the comfort of a disease-free environment. In fact, telecommuting has become a viable option for nearly 3.3 million people (approximately 2.6 percent of the U.S. workforce), according to the latest American Community Survey data

from 2012. And, there are more than 316,000 disabled employees who regularly work from home using the Americans with Disabilities Act "reasonable accommodation" clause.¹

Laura, a software engineer in Seattle who suffers the symptoms of Guillain Barré syndrome, found that telecommuting was a perfect solution for her. "After eight years of being sick, I was exhausted," she said. Like many patients with chronic illness, working outside of the home eventually became unrealistic. She finally conceded that she had no choice but to restructure her life and find a way to reduce her time away from home. Since Laura had maintained a positive relationship with her employer, she decided to ask if they were flexible. Her boss agreed to restructure her workload and to allow her to telecommute on a trial basis. She was able to work from home two to three days a week and go into the office on the other days.

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Laura admits her biggest concern was that co-workers would think she was slacking off rather than working. "There was a misperception that if they didn't see me at my desk busily chugging away, then I was not working," she explained. "I really had to increase communication when I worked from home. I constantly updated my team about projects and worked hard to stay in the loop." This strategy seemed to pay off because her boss agreed to continue allowing her to telecommute, and Laura was able to get the rest she needed.

Modifying the Workload or Work Day

Some patients find they simply cannot telecommute because the nature of their job requires them to be physically present at the job site. In this case, when a patient's illness interferes with their success to manage the workload, employees may want to approach employers

Strategies for Maintaining Your Current Job

Workers with chronic illnesses face uncertainty and are forced to worry not only about their health but about their jobs. And, protections afforded chronically ill workers in the United States are thin and somewhat vague. To protect their health and their jobs, workers must navigate employers' policies, which may include short- and long-term disability plans, as well as a patchwork of federal laws and regulations. Here are a few strategies to help you maintain your current job.

Talk to your supervisor. If you have a condition that could interfere with your performance, tell your supervisor. Be honest. Explain what your condition is and how it might affect your work. "People are often afraid of being discriminated against," said Rosalind Joffe, a career coach who counsels people with chronic illnesses.¹ A supervisor who understands what is wrong is less likely to make false assumptions about what you can and cannot do.

Ask for modifications. If your illness meets the definition of a disability, your employer is required under the Americans with Disabilities Act (ADA) to make reasonable accommodations to your job or work environment. A disability is defined as a physical or mental impairment that substantially limits one or more major life activities. Although your illness may be episodic or controlled by medications, it is still a disability, according to a recent amendment to the ADA.

If you are not sure what type of accommodations you are entitled to or how to ask for them, contact the Job Accommodation Network at (800) 526-7234. This service is provided by the

Department of Labor. In general, the network recommends that you put your request to your employer in writing. But, if you work in a small, informal setting, that may not be necessary.

Know policies. You can learn about your company's time off and sick leave policies by going to your company's intranet or speaking with its human resources department. If you need to take a few weeks or months off due to your illness, research your company's short- and long-term disability plans. Disability policies usually allow you to take a specific time off at reduced pay.

The Family and Medical Leave Act allows employees to take up to 12 weeks off each year for medical or family emergencies — but without pay. You can use the 12 weeks at any time, and you may take the time intermittently or all at once.¹

Explore options. If you can't continue to work at your current job due to your illness, find out whether you could work part time or could even take a different job in your company. If neither is feasible, explore new career possibilities. Be flexible and open to change.

Sometimes patients don't have the choice to work or not to work. If illness prohibits a patient from working altogether, Social Security disability insurance can offer some relief. The process is lengthy, and employees must prove that they cannot work at any job. The amount paid is based on lifetime earnings; the number can be found on the annual statement from the Social Security Administration. Payments are modest, but once a patient receives disability payments for two years, they automatically qualify for Medicare coverage.

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2. Lameire, J. What Do You Mean You Can't Work? Yahoo Voices, Jan. 16, 2013. Accessed at voices.yahoo.com/what-mean-cant-work-11972268.html?cat=5.

about workload redistribution or modified work schedules. It's important to talk openly about realistic expectations in finding a solution that works.

This was how Cindi, a retail assistant in Southern California, handled it. Diagnosed with common variable immune deficiency, Cindi also reached a point where she could no longer work full time due to her chronic illness. "It was tough because I didn't want to admit my illness was interfering with my work," she explained. "It felt

like I was being controlled by my illness, so I resisted giving in." She had exhausted her leave time and was struggling with chronic fatigue, especially in the morning. Constant tardiness made her look unreliable, and she knew something had to change. Not wanting to lose her job, Cindi hesitantly told her boss about her chronic illness. "I think my boss was actually relieved when I finally told her what was going on," she said. They were able to develop a schedule that allowed Cindi to arrive

HIZENTRA®, Immune Globulin Subcutaneous (Human), 20% Liquid
Initial U.S. Approval: 2010

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use HIZENTRA safely and effectively. See full prescribing information for HIZENTRA.

WARNING: THROMBOSIS

See full prescribing information for complete boxed warning.

- Thrombosis may occur with immune globulin products, including Hizentra. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.
- For patients at risk of thrombosis, administer Hizentra at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

INDICATIONS AND USAGE

Hizentra is an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated for the treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

DOSAGE AND ADMINISTRATION

For subcutaneous infusion only. Do not inject into a blood vessel.

Administer weekly or biweekly (every two weeks).

Dosage

Before switching to Hizentra, obtain the patient's serum IgG trough level to guide subsequent dose adjustments.

Weekly: Start Hizentra 1 week after last IGIV infusion

$$\text{Initial weekly dose} = \frac{\text{Previous IGIV dose (in grams)}}{\text{No. of weeks between IGIV doses}} \times 1.53$$

- Biweekly: Start Hizentra 1 or 2 weeks after the last IGIV infusion or 1 week after the last weekly Hizentra infusion. Administer twice the calculated weekly dose.
- Adjust the dose based on clinical response and serum IgG trough levels (see *Dose Adjustment*).

Administration

- Infusion sites – 1 to 4 injection sites simultaneously, with at least 2 inches between sites.
- Infusion volume – First infusion, up to 15 mL per site. Fifth infusion, up to 20 mL per site, then to 25 mL per site as tolerated.
- Infusion rate – Up to 15 mL per hr per site. Increase to 25 mL per hr per site as tolerated.

DOSAGE FORMS AND STRENGTHS

0.2 g per mL (20%) protein solution for subcutaneous injection

CONTRAINDICATIONS

- Anaphylactic or severe systemic reaction to human immune globulin or components of Hizentra, such as polysorbate 80
- Hyperprolinemia (type I or II) (Hizentra contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

WARNINGS AND PRECAUTIONS

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including Hizentra.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- May carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

ADVERSE REACTIONS

The most common adverse reactions observed in $\geq 5\%$ of study subjects were local reactions (i.e., swelling, redness, heat, pain, and itching at the injection site), headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, rash, pruritus, vomiting, abdominal pain (upper), migraine, and pain.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

DRUG INTERACTIONS

The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.

USE IN SPECIFIC POPULATIONS

- Pregnancy: No human or animal data. Use only if clearly needed.
- Pediatric: No specific dose requirements are necessary to achieve the desired serum IgG levels.

Based on September 2013 version

later and reduce her work hours each day, resulting in her working 65 percent of her full-time hours. The downside of this new schedule was that working part time also resulted in part-time pay. Yet, Cindi said it's the only way she could manage keeping her job and her health. She has managed to juggle the financial changes with the help and support of her family, and has moved in with her sister and brother-in-law.

Retraining

Sometimes the nature of a patient's illness makes the current job unsustainable. In such cases, retraining within a current field or even changing careers can be an option. Some companies will provide retraining opportunities, but if that is not an option, patients can look into short-term vocational classes, certification or technical classes at community colleges, career-oriented classes in secondary schools, apprenticeship programs, and a variety of other programs and institutions that offer job-specific skills.

The federal government plays a major role in training the disadvantaged and displaced, funding many major

programs through the Department of Labor and Department of Education; it also funds the task of providing reemployment services.² Such was the case for Daniel, a self-employed carpenter from Georgia who needed their support services.

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Coping with the physical limitations of his chronic illness, Daniel found himself struggling to make ends meet as his disease state progressed. The chronic flare-ups were occurring more often, and Daniel was unable to meet the physical demands of his job, where he had to climb ladders, work in tight quarters and lift and manipulate heavy objects. As a self-employed contractor, when he was unable to work, there were no sick days or vacation days



to fall back on. Daniel found himself facing the reality that he would not be able to continue working in the only field he'd known since graduating high school. The pressure to provide for his family was enormous as the medical and household bills began to mount quickly.

Even though Daniel thought he'd never be in a classroom again, he enrolled in school and retrained for a new career in technology with fewer physical demands. "That year of going to back school, coping with debt and managing my illness was incredibly challenging," Daniel said. "My wife had to take on more financial responsibility, and that was hard on our family, too. But, the doors of opportunity that opened have allowed me a new lifestyle." He now works for the IT department of a local school district, repairing and updating classroom computers and laptops. "The environment and work schedule are more conducive to juggling my medical treatments, and I am not hindered by my physical limitations. And, the medical insurance is a huge plus!" he explained.

Opening Your Own Business

Statistics from the U.S. Corporations of America show that one in every 153,700 people owns their own business. And, in fact, more than half of all U.S. businesses are based out of an owner's home.³ While some may see starting a business from home as a luxury, it is the only way to survive for many with chronic illness.

Rachel had always loved her job as a pediatric nurse, and her employers were accommodating about flexing her work schedule when she was ill. But, eventually, even working minimally became too much. "I had a feeling of exhaustion so profound I could hardly get through an hour of work, let alone a full day," Rachel said. "I could no longer manage many of the simplest tasks of daily living, let alone working. I had gone from five days a week, to four, then three, but eventually two even became too much." That's when Rachel knew her job situation had to change. Rachel began to look at what she could do from home.

She had a small savings and decided to use her financial resources to start her own business. After assessing her skills and realistically looking at her abilities, Rachel opened a nanny service providing short-term care for sick kids of working parents. "I saw a need while I was working at the pediatric office and thought of how I could fill that need," she explained. She turned the extra room in her home into a home office, and is able to conduct most of her business by phone. There is very little overhead, and

referrals have come from the parents she met while nursing. "The best part of owning my own business is having the flexibility to take care of myself," she said. "I can sleep when I need to and schedule meetings on my time." Rachel states that a big advantage is that it's much easier to schedule her infusion therapy, without worrying about the disruption to work. She says that often she infuses while working. But, there is also a downside to working at home: She misses the social connections of being in an office with other professionals. To avoid the feelings of isolation that can come from working at home, Rachel is conscious to create an online network that enables her to stay connected professionally, as well as socially.

Finding the Right Fit

Some patients find their financial situations have changed little since they became ill; their symptoms are mild, and they can continue to work with a few adjustments. For others, however, financial pressures can be great, even overwhelming. Some patients live alone with little or no income and struggle to make ends meet because they can no longer work. Many patients are somewhere in between, stressed to some degree, but able to maintain a lifestyle more or less similar to the one they had before becoming ill. The bottom line: Each person's illness is different, and each person's ability to cope and work with illness is different.

Finding the right work environment that can accommodate the challenges of chronic illness is difficult. Success is dependent on the willingness to make adjustments. The key is to be flexible and find the solution that's right for you. ■

ANNABEN KAZEMI is the patient advocate for IG Living magazine.

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3. SBA.gov. Home-Based Businesses. Accessed at www.sba.gov/content/home-based-businesses.

Resources

- Career One Stop: www.careeronestop.org/TridionMultimedia/mySkillsmyFuture_tcm24-7103.pdf
- U.S. Department of Labor: www.dol.gov/dol/audience/aud-unemployed.htm