





ILL IN A DAY'S WORK

When a woman is diagnosed with a chronic disease like **cancer, M.S. or lupus**, she is often at the peak of her earning power and productivity. How do you choose between your livelihood and your life? *More investigates*

IN HER BUSTLING pediatric office in Severna Park, Maryland, Faith Hackett, MD, is explaining to a toddler's young mother that she can't reach down for the boy or give him a hug, even though he's pulling at her for attention. "I'm sorry," she says, steadying herself on the exam table for a moment, "but I just can't pick him up." Realizing that something has changed since their last visit, the mom jumps up and draws her two-year-old back into her lap. Hackett looks drawn and tired. And she is limping slightly on her left leg.

What her little patients' parents don't know is that in January 2008, Hackett, 52, ruptured a disc in her lower back. During an MRI, doctors discovered that two other discs were also damaged, bulging from the wear and tear of bending over children for so many years. Since her diagnosis, the pain in Hackett's back and leg—a result of the disc injuries—has worsened considerably. For months, Hackett has often been unable to sleep an hour at a stretch before the pain wakes her again. The effect on her work has been profound: She can't pick up

By Donna Jackson Nakazawa

Photographed by Levi Brown

anything heavier than 10 pounds, about the size of an infant. “That means that all those yummy kids I would normally lift into my arms—I can’t hold them anymore,” she says. “Nor can I calm a struggling, unhappy child, and that’s been really hard for me.”

In her 22 years of practice, Hackett has been known to meet patients at her office at 11 PM or sit with a sick child’s parents at the hospital. But now, the slightest wrong turn to grab a stethoscope can have agonizing consequences; more than once she has had to head home and lie down on the floor, while her husband, who practices internal medicine, pulls on her leg to put traction on her spine. She has also cut back her work hours in order to spend more time seeing her own doctors and physical therapists. She says she never realized before “how much stamina I needed for the job I do and how much that stamina can be affected by pain and lack of sleep.” In many ways, Hackett took her capacity to work for granted—until she developed a chronic illness.

SICKNESS AS ROADBLOCK

Today, a growing number of midlife women face an array of chronic diseases that blindside their careers. Managing their health forces many of them to take pay cuts, scale back their aspirations and give up socializing and networking. As a result, they face financial consequences that can be profound: The *Journal of the National Cancer Institute* recently reported that the typical working woman with breast cancer loses more than a quarter of her income in the 12 months following the start of her treatment. One in 10 female patients loses as much as two thirds of her income as a result of missed work or reduced hours, and women are even more likely to suffer large wage losses if they live a significant distance from the medical center where they undergo treatment.

Women are especially susceptible to certain kinds of chronic illness. For instance, they are four times more

HOW DO YOU GET THROUGH THE DAY?

“I have scleroderma and rheumatoid arthritis. I wear a pendant that says **EVERY DAY MATTERS**, and whenever I touch it I am reminded of life’s meaning, my meaning.”

—Tori Anderson | 49 | radio personality in Hancock, Maryland

likely than men to be diagnosed with an autoimmune disease, in which the body’s immune system, acting on misread signals, turns on itself. There are more than 80 such diseases, but women in their forties and fifties are particularly vulnerable to Hashimoto’s thyroiditis, Sjögren’s syndrome,

polymyalgia, rheumatica and rheumatoid arthritis, among others. Rates of many autoimmune diseases have doubled and tripled in recent decades.

But chronic illness takes myriad forms: There is back pain, which also increases in midlife, and which tends to be more common in women than



in men. Nearly a third of women ages 45 to 64 suffer from low back pain (though certainly not all cases are as serious as Hackett's). And there is arthritis, which affects roughly 12 million women from ages 40 to 60—that's more than 26 percent. Cancer has now also become a chronic disease for many Americans: About 200,000 women ages 40 to 59 suffer from some type of the disease, which is more than the number of afflicted men of the same age. Approximately six percent of women between 45 and 64 have heart disease, which is now the second leading cause of death for women in that age group. All told, nearly 133 million Americans—more of them women than men—suffer from a chronic health condition.

And I am one of them. In 2001 and again in 2005, I suffered paralysis brought on by Guillain-Barré syndrome, in which the myelin sheaths, which wrap like a protective insulation around the body's nerves, are destroyed by the immune system. After each episode I had to labor for months to regain the use of my limbs. At one point after the second attack, four out of five doctors I visited informed me, gently, that I might never work again. The only exception was my own neurologist, who knew I had written several books and worked as a journalist and lecturer. "You're a fighter," he said. "You're going to fight your way through this and get back to what you do. Whatever happens, don't give up on your work."

Over the next five months, I regained enough feeling in my legs to walk again, and in my hands to type again, which was almost as important to me. I began a study of chronic disease and spent the next three years interviewing women of all ages, professions and stages of illness. And although I needed custom-made wrist braces to work at a computer, I wrote a book, *The Autoimmune Epidemic*, investigating the rising incidence of autoimmune disease; it was published in 2008. All told, these dual episodes of paralysis and physical rehabilitation (as well as bouts with three other autoimmune diseases) added up to 12 months of lost time in my early- and mid-forties when I was unable to get out of bed.

Little by little, I managed to resume my career, mostly working from home. I learned how to pace myself, lecturing to a crowd of 1,000 people one day and spending the next two in bed. Even so, I rarely revealed to my editors, colleagues and clients the physical challenges I faced every day. I didn't want them to question, even unconsciously, whether I could still deliver the goods.

Faith Hackett was like me. When she first fell ill, she tried to continue her day-to-day work life as if nothing had changed. But as her condition worsened, "the way I looked sometimes worried people," she says. "If I was having a painful spasm, I had to hold on to the examining table. I realized that they needed me to talk about

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"I used to say yes to everything, but now that I'm ill [with Hashimoto's thyroiditis] I let younger and healthier coworkers say the extra yes—it's their turn now. But when a client asks, 'How are you?' I always say, 'Excellent!' even if I feel poorly. When I do that, I feel better. *Sometimes when I'm preparing to meet a client, I say to myself, showtime!*"

—Enid Fox | 55 | nutrition consultant, Sunnyvale, California

WHAT ARE YOUR LEGAL RIGHTS AT WORK IF YOU GET SICK?

Two federal laws address this question for employees of private companies. The first is the 1993 Family and Medical Leave Act, which grants seriously ill employees up to 12 weeks unpaid leave in a 12-month period. You can take the time off all at once, in shorter blocks or in increments as small as 15 minutes. So someone who needs to recover from a series of surgeries could take a week every few months to recover, or a person with mental illness could leave early on Wednesdays to see her therapist.

The other law that protects the rights of the chronically ill is the 1990 Americans with Disabilities Act. In general, it states that an employer has to make "reasonable accommodations" to workplace rules to allow a disabled individual to perform her "essential job function." The catch is that a chronically ill employee doesn't automatically qualify for coverage; she has to prove she has an impairment that adversely affects more than one everyday activity, like walking. A January 2009 amendment to the ADA will help an employee make her case by mandating that the limitations of a person with chronic illness be determined by looking at her condition when it's active, not in remission.

—PATTI GRECO

IF YOU ARE THE MANAGER

If a sick employee asks you to discuss ways to make her job more doable, you—or another representative of the company—are required by law to have the conversation. There is no federal paperwork to file, but the hope is that you and she can arrive at a compromise to help you both do your jobs more efficiently. Here are some guidelines to help you along the way.

NEGOTIATE TERMS

According to the Americans with Disabilities Act, you should not have to make any arrangements that will place “undue hardship” on your business. So if you run a software company and a diabetic employee asks to schedule a regular break to check her insulin level, that is probably reasonable. But if you own an ad agency and one of your staff says she can’t attend morning sales pitches because she has Crohn’s disease and often wakes up with an upset stomach, you may want to suggest an alternative solution (maybe she sets her alarm earlier so she has more time to recover).

If she disputes one of your suggestions on medical grounds or you want a physician to weigh in, you can legally arrange for an outside consultation. Likewise, you have the right to review an employee’s medical records (but only those that pertain to her disability claim). You can also enlist the help of an outside mediator, such as the Job Accommodation Network (jan.wvu.edu), which provides arbitration free of charge.

TALK TO HER OFTEN

Your employee needs to know she can tell you if she’s unable to finish a project without worrying she’ll be fired. And you need to know that you won’t be blindsided by late reports. Try scheduling regular meetings to discuss whether your arrangement is working. If it’s not, you can always renegotiate the deal.

If you are meeting your employee’s expectations, you can and should hold her to the same performance standards as a healthy staff member. “Many managers think, I can’t ask her to do anything else because she’s sick,” says Roslyn Stone, CEO of Corporate Wellness, a health services company in Mount Kisco, New York. In fact, you should not lower your expectations of an ill employee or shy away from constructively criticizing her performance. “The biggest mistake managers make,” Stone says, “is thinking they can’t commence disciplinary action with an employee who has a chronic medical condition.”

IF SHE REQUESTS A MEDICAL LEAVE

First know you’re entitled to 30 days’ notice (unless the leave was unforeseeable), medical proof supporting her need for time off and a second or third medical opinion if you want it. Once the leave is in effect, you can legally request periodic reports on her status (without asking for personal or private information) and her intent to return to work. —P.G.

it, to explain why I was acting the way I did.” Ironically, even as Hackett’s condition worsened, coworkers still had trouble registering how sick she truly was. “People don’t pick up that you’re in excruciating pain unless you tell them directly,” she says. “They may not understand that the reason you’re behaving differently is because you are in agony.” Often, the illnesses women face are largely invisible to casual observers, even those who know them fairly well. In fact, 96 percent of people who suffer from a chronic health problem live with an illness that has no surface manifestation—they don’t use a cane, wear a cast or appear disfigured. They seem healthy enough and, as a result, others often expect more from them than is physically possible.

Even Hackett’s staff didn’t pick up on the severity of her illness until she called them into a meeting and said outright, “Look, if we keep booking so many patients, I’m going to collapse. Either we cut back right now or I won’t be here at all—I’ll be forced to have surgery and be out in recovery for weeks.”

REAL BIAS, HARSH PENALTIES

“A great deal of stigma is attached to chronic illness in the workplace,” says Stephanie Woolhandler, MD, codirector of the internal medicine fellowship program at Harvard Medical School. “The system isn’t very fair to anyone who is sick. But it is particularly unfair to women, who are more likely to suffer from chronic illness during the prime working years.” Women who are sick find themselves in a triple bind: unable to excel at their career because they are sick; unable to take good care of their health because they are working; unable to quit because they need the health insurance they can get only through a job. “If you have to quit working altogether, the options for health insurance are pretty dismal,” Woolhandler says. “You’ll be eligible for COBRA, but you’ll have to pay the full premium from your own pocket. Many people on COBRA incur huge debt and end up in bankruptcy. When



COBRA runs out, you may qualify for Medicare. Or you may spend until you reach poverty level and get Medicaid. But if you have cancer, chances are that you cannot buy private insurance after COBRA ends. No one will sell it to you.”

This makes the threat of losing a job all the more dire. Woolhandler treats many women who don’t want medical records released to their employer because they fear it will harm their career, or worse. “My experience is that when a woman feels paranoid about letting her employer know about her chronic illness,” she says, “there is usually a very good reason.”

Michelle Nofer, a 48-year-old lawyer in Philadelphia, agrees emphatically.

As a specialist in employment issues, she spent much of her career telling colleagues, “You have to let people take time off when they are ill, you can’t give them less of a raise, and you must never let an employee’s illness color how you view them.” Yet up until very recently—when she announced she was taking an extended leave of absence—Nofer chose not to tell her own office about the life-threatening health condition she’d been facing for eight years.

In October 2000, just before her fortieth birthday, Nofer, who for months had experienced severe fatigue, unremitting pain and swelling in her legs so severe she could barely shuffle across a room, was diagnosed with a

serious autoimmune disease known as IgA nephropathy. (This occurs when IgA—a protein that helps fight infections—settles in the kidneys and begins to attack the organs themselves.) Several months later, she was diagnosed with an autoimmune-related disease, fibromyalgia, a disorder that causes severe muscle pain and fatigue. Although today the IgA nephropathy is stable, for years Nofer required a combination of drugs to keep the disease at bay (about a quarter of adults with IgA nephropathy develop total kidney failure). And even now, because of the fibromyalgia, she has days when her only choice is to “either become a zombie on pain medication or go to bed for the day.”

At the office, Nofer confided her situation to only a few trusted people, including her boss, with whom she had a close relationship. She felt she owed her the truth, that given the highly demanding nature of the job, Nofer would never have been able to explain away a pattern of sudden absences, unanswered phone calls and work-at-home days. When she was ill or at medical appointments, the secretary fielded phone calls. She and the boss kept Nofer’s “wellness cover,” helping her check that nothing fell through the cracks. Nofer’s hundreds of colleagues “assumed that I just kept catching every virus and flu possible,” she says. “People had no idea I’d been dealing with a very crippling illness and years of constant flare-ups.”

Workers suffering from chronic illness also face a less obvious professional disadvantage: They need to cut

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“I’ve deliberately kept my commute as short as possible because with my condition [fibromyalgia, arthritis and irritable bowel syndrome], I just can’t get run down. And I work ahead whenever I can. Procrastination causes stress I don’t need. *Whenever I’m making decisions, I always remember KISS: Keep It Simple, Stupid.*”

—Janet Kirk-Greenblatt | 41 | music teacher, Easton, Pennsylvania

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“It’s hard for me to see my girlfriends running on normal energy and going out to movies, restaurants and celebrations on top of a 40-hour workweek, knowing that, as a lupus patient, I can’t. But I try to respect that taking care of work and home are all that I have the energy for. *I also don’t carry a company cell phone, so when I’m off, I’m off.*”

—Joan “Connie” Dubbs | 56 | office manager, Oceanside, California

down on their networking, putting in less after-hours face time at the office and hosting fewer client dinners than their colleagues. “After I developed two chronic diseases, I just wasn’t able to go to the social and trade events anymore,” Nofer says. “I couldn’t stay on the national scene. People suddenly saw me as not participating as much as everyone else, and yet they had no idea why.”

Why did Nofer go to such great lengths to keep her illness a secret? “When you work in employment law, you know that discrimination against sick people is very real,” she says. “We tend to suspect that when someone gets sick they must be weaker than we are in some way, that they must have done something wrong. I think we do that to differentiate ourselves from them; it’s our way of telling ourselves, this could never happen to me.” Nofer says she sees this kind of prejudice in the business world every day. “It’s kind of like the mommy track,” she points out. “We like to say we don’t view the career potential of women differently if they are juggling work with raising kids, but we do. Well, the mommy track is in the same league as the sick track.”

And yet Nofer is speaking openly about her illness now—partly as a result of being interviewed several times for this article. “I really heard my own story for the first time,” she says. “It rang out loud and clear how crazy it was to be working around the clock while pretending I wasn’t ill—then secretly recuperating at home, tapping away on my BlackBerry. The more I talked about how I try to cope, the more I realized I’m

not coping.” As she started to see the bigger picture, the pattern of her life emerged. “It suddenly seemed absurd that I have never really tried to half-way take care of myself,” she says. “I realized that if I want to stay alive for my two sons, I had to break the pattern.” Indeed, she sees her recent decisions—first to come clean with colleagues, then to take a leave of absence, and finally, just this fall, to step down altogether—“as long overdue first steps to taking care of me.”

CREATIVE COPING

For women with chronic illness, career-tending requires a high level of inventive strategizing, scripting and maneuvering, and every woman I talked to has developed her own techniques. Claire Ganz was 42 in November 2006 when she was diagnosed with Guillain-Barré syndrome. At the time, she was running two small businesses from her home in Santa Fe, New Mexico: Bringing Dreams into Play, which advises small companies on how to market their products, and Martha’s Vineyard Totes, which sold beach bags. When Ganz was diagnosed, she had been working for nine years building her businesses. “I felt I was on my way,” she says. But she had to put both aside to spend a month in the hospital, receiving intravenous treatments of other people’s healthy immune system proteins. She came home in a wheelchair, unable to walk, only to discover that she had lost many of her clients.

Now, more than two years later, Ganz is walking again, though always with difficulty, and she has rebuilt her client base. But her outlook on work

has been forever changed. “When you run your own business, you’re not just selling your services to clients, you are selling yourself,” she says. “And when a client sees you have trouble getting across the room, relationships can suddenly go cold.” When clients meet Ganz for the first time in a conference room, “My disability is obvious,” she says. “I can’t get up out of a chair without crutches.” Ganz’s strategy has been to have a script that she follows when someone inquires; it helps her to feel she is in control of what people know. “If people ask, I simply tell them, ‘I fell ill with an autoimmune disorder and I’m getting better;’ ” she says. “What I mean by that is: Even though I may not be getting better physically, I’m getting better at living with what I have.”

Michelle Nofer gets support and practical advice from several interactive health Web sites that combine information with online peer support. The Department of Labor’s Job Accommodation Network (jan.wvu.edu) offers concrete suggestions about how employers and employees can accommodate the specific demands of dozens of illnesses. Nofer says she has also found comfort at keepworkinggirlfriend.com, which addresses the professional issues of women with chronic illness. (Another good resource is cancerandcareers.org.)

All the women I interviewed rely heavily on technology. “In the age of the BlackBerry and the computer, you can be home in bed and no one knows,” Nofer says. “For years, that’s how I got through.” Hackett answers e-mail from home at night. “I prefer talking to parents face-to-face,” she

says, "but I can't. So I go home and write to them one at a time." Ganz keeps her computer plugged in next to her bed and logs on before she tries to get up. "My legs don't work so well in the morning, so before I stand up I need to do 45 minutes of exercises to wake up my legs and feet so that they can hold me," she confides. While exercising, she's also online, answering e-mails. "Working while I move on my legs keeps me from getting down about my situation," she says. "I need to be connected to the world."

Ganz also uses creative strategies to compensate for the effect she fears her crutches may have on clients. "I make sure that I have beautiful over-the-shoulder accessories—purse, laptop case—so that I don't have to struggle to carry anything when I enter a client's office," she says. And she's much more careful about which clients she accepts. Ganz says she has had to "let

go of the pleaser aspect of who I am. I don't say yes to anything I don't really want to do. It's a hidden blessing to learn to let that go."

PASSION PLAYS A PART

For many years, Linda Johnson, 60, served in a senior management position at a local Washington, D.C., bank. She was working there in December 1993, when, at age 45, she was diagnosed with breast cancer. Johnson had one mastectomy in 1994 and a second in 1996, and continued working throughout her treatment. Then her mother died of breast cancer. "When that happened, I realized there were things I wanted to do in life that I hadn't done yet," she says. Around the same time, the bank where she worked announced a merger. "People would have to be laid off," she says. "It was going to be incredibly stressful, and I didn't want to be the one to deal with it." She had always gotten health insurance through her husband, so she quit. "It was a huge decision," she says. "But one I knew I had to make."

Johnson started to do some pro bono work. Two years later, she got a call from a good friend who asked if she would help out a nonprofit that needed an executive consultant. The helping out turned into a full-time position, and until June 2008, Johnson served as head of human resources for AABB (formerly the American Association of Blood Banks), the nonprofit which represents most of the nation's blood banks. "Because I started as a freelance consultant rather than as an employee," she says, "I was able to be very open and up-front about needing time to deal with my health." AABB told Johnson that if she came to work for them full-time, she could telecommute whenever necessary.

In 2005, at 57, the breast cancer metastasized into her bones. So Johnson started telecommuting two or three times a month from a chemo infusion room, her laptop on her knees. "I have a number of people in

the office I'm very close to," Johnson says. "They ask very nicely, without prying, how they can help. They know that I come in later in the day because early morning is when I have the most trouble with nausea from the chemo. They know that I keep a body-length cushion by my desk and if I'm really tired at lunchtime, I just unroll it and lie down right there on the floor. I don't ever want to have to try to hide any of that." Studies show that having a high degree of social support and empathy from others is critical in helping patients maintain a positive attitude when suffering from a chronic disease. Johnson smiles when I tell her about one woman I interviewed who has lupus and whose colleagues have been known to roll her in her desk chair all the way to the conference room when she's having a tough day. "It isn't what you want—to have your colleagues see you that way," she says. "But it's so good to know that you don't have to hide what's happening to you and that they'll support you in whatever state you are in."

In the midst of balancing a chronic illness with a career, many women—myself included—discover just how passionate they are about their work. Quite often, it is a combination of desire and well-honed personal strategies that allow us to keep doing the work we love while trying to stay as healthy as we can. "Wanting to help others is a huge part of who I am in my work," Ganz says. "I love getting up every day and helping people give new life to the product they've created. And I have no plans to give that up." For her part, Linda Johnson feels that her illness was an opening to another way of life. "For a long time, I was able to balance my job of taking care of myself with a career I loved," she says. "I don't want to sound too mushy, but I found my calling." Faith Hackett feels the same way. "I have a job I love," she says. "Just knowing how much a toddler wants to give me a hug—how can that not make me smile every day?" 🌸