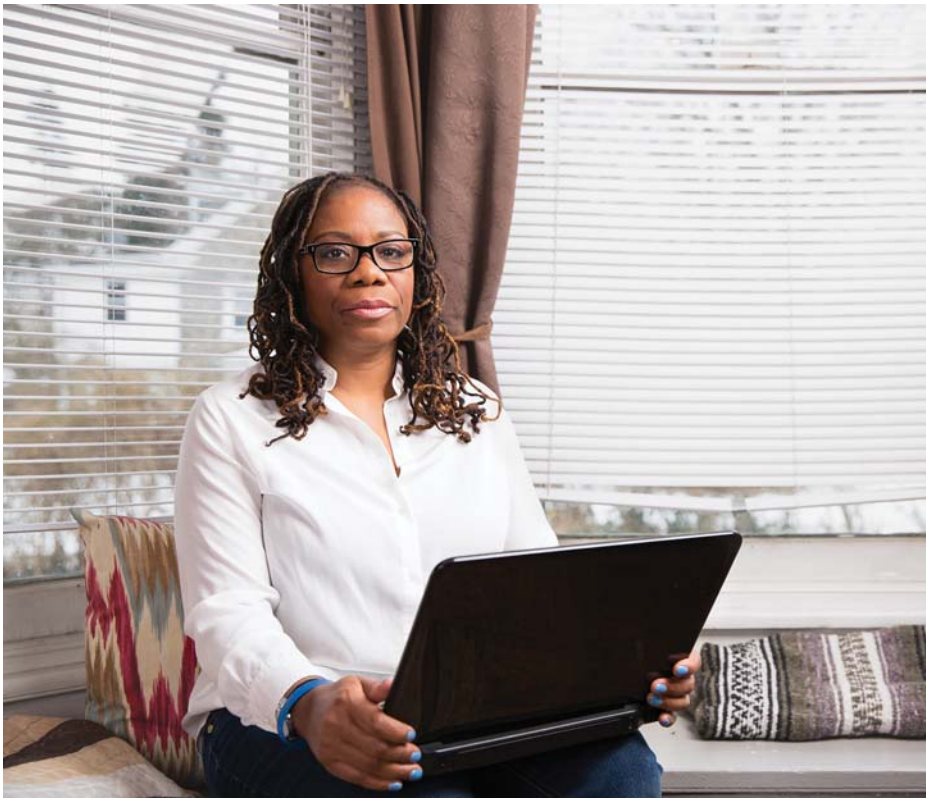

Sick at work: Kim Hall Jackson, an event planner in Philadelphia, underwent surgery and chemotherapy after being diagnosed with colorectal cancer. Supportive at first, her employers later resisted the accommodations Jackson needed to make the frequent follow-up appointments and testing necessary to guard against the disease's spread.

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Working With A Chronic Disease

As millions of Americans with chronic and serious illnesses continue going to work, their employers are finding new ways to adjust.

BY T. R. GOLDMAN

For Kim Hall Jackson, it wasn't the months of chemotherapy and radiation that proved to be the most onerous part of her cancer diagnosis. She left work early every other Friday and was usually back at her job at a large convention center the following Monday, despite the chemo's arduous side effects. The ugliness at work, she said, began after her treatment was over.

Jackson's doctors had initially diagnosed her with stage 1 colorectal cancer, but the pathology report two weeks after her surgery confirmed that it was actually stage 3, which meant the cancer had spread to her nearby lymph nodes. So after her chemo was completed, her doctors remained especially vigilant, scheduling regular blood work, scans every three months, and time-consuming colonoscopies every six months.

"'Why do you have three appointments in one month? We're all done with your cancer,'" Jackson recalls her supervisor telling her. "And I was like, 'It's not that simple, I wish it were.' She didn't get it."

The badgering and the skepticism from her boss continued for over a year, Jackson says, until her position was eventually eliminated in 2013.

"If I had had knee surgery and had a cane, they can see I still have to go to physical therapy," says Jackson, who reached a settlement with her employer initiated under the Americans with Disabilities Act (ADA) of 1990 and is now an independent event planner in Philadelphia. "With cancer, people don't understand there's ongoing treatment. They don't understand what they can't see."

It's a common complaint, and one of the more knotty subsets of a larger societal question: How should employers, both large and small, handle the myriad special needs that an employee with a chronic disease might have—from frequent snack breaks for a person with diabetes to regular and time-consuming visits to the doctor as in Jackson's case, which can continue for years after an illness is diagnosed.

Chronic disease—a catchall phrase for illnesses that require ongoing medical attention—includes dozens of illnesses such as heart conditions, cancers, inflammatory bowel diseases, depression, multiple sclerosis, lupus, bipolar disorders, and chronic fatigue syndrome.

Thanks to an aging population, earlier detection, and better treatments, more people are living with chronic disease than ever before. In the United States, cancer death rates have dropped 25 percent since 1991,[1] and there are now some 15.5 million cancer survivors in this

Photograph by Colin M. Lenton

country—a figure that is expected to reach 20.3 million by 2026, according to the American Cancer Society.[2]

Nearly one in five Americans ages 18–44 have multiple chronic conditions, according to an analysis of data for 2006 and 2010 from the Household Component of the Agency for Healthcare Research and Quality's Medical Expenditure Panel Survey.[3] But virtually half of all Americans ages 45–64—the prime employment years for many jobs—now live with more than one chronic condition. And work remains a bulwark of their lives for the same reasons that it does for the rest of the population: economic imperatives and psychological fulfillment.

"For most of us, especially in America, work is part of our cultural fabric. We almost invariably start a conversation with 'What do you do?'" notes Rebecca Nellis, the chief mission officer for Cancer and Careers, a national nonprofit organization that helps people with cancer navigate the work environment. "I love my job," she adds. "But I'd much rather talk about my favorite vacation."

From 'Accommodation' To 'Adjustment'

Though the United States lags behind other developed countries in many social indices—weeks of paid maternity leave, vacation time, and sick days, for example—it is a standard-bearer for the civil rights of the disabled. "The ADA was the world's first comprehensive law guaranteeing equal rights to persons with disabilities," trumpeted the US State Department's website last year, when the ADA celebrated its twenty-fifth anniversary.[4]

While the ADA obligates employers with fifteen or more employees to make their workplaces accessible to people with disabilities—leading to the now ubiquitous wheelchair ramps and blue-signed handicapped parking spots—it also requires them to make "reasonable accommodations" so that a disabled employee can continue to perform the "essential functions" of his or her job.

Though the popular conception of a person with a disability remains someone in a wheelchair, amendments to the ADA that took effect January 1, 2009, greatly expanded the definition of *disability* to include any impairment that "substantially limits" a person's ability to perform one of eighteen "major life activities"—which include lifting, bending, concentrating, thinking, and working. Calling working a "major life activity" might seem a tautology, but it gets to the heart of what Congress intended the law to mean: A disability should "in no way diminish a person's right to fully participate in all aspects of society."

Major life activities were also expressly noted to include the operation of eleven "bodily functions"—everything from bowel and bladder to "normal cell growth," to "reproductive functions." The upshot is that almost any chronic disease, because it "substantially limits" at least one major life activity or bodily function, is covered under the ADA.

In fact, many people whose conditions are included in the act never think of themselves as having a disability, says Anne Hirsch, who codirects the Job Accommodation Network (JAN), a free consulting service funded by the Department of Labor's Office of Disability Employment Policy. "They just don't think they see or hear as well as other people," she says, although in reality the employer should provide, if asked, a "reasonable accommodation"—perhaps a large-screen computer monitor, a telephone hearing amplifier, or a vibrating pager.

Larry Lorber, who represented the US Chamber of Commerce during the ADA amendment negotiations, says that under the ADA, employers must find an accommodation that "allows you to jump over the disability so you can do the job.... The notion that there's one set way to do a job, that this is how it's always been done—that doesn't cut it anymore."

Of course, the accommodation must be "reasonable"—a server in a restaurant cannot telecommute, for example—and it cannot impose an "undue hardship" on the employer. While such terms are inherently litigable, the norm, according to disability experts, is that most accommodations are neither costly nor burdensome. If, for example, an employee's illness makes her especially sensitive to smells, move her desk away from the company canteen. If an employee has difficulty walking up the stairs to the printer, move the printer downstairs.

"The myth that accommodations are expensive is a myth that has been perpetuated for decades," notes Louis Orslene, who codirects JAN with Hirsch.

It also appears that accommodations like flexible scheduling are granted less frequently among businesses with fewer than fifteen employees—businesses to which the ADA does not apply—an exclusion that "disproportionately affects low-income workers," according to the results of a study published this month in *Health Affairs*.[5] The study followed 267 employed women being treated for early-stage breast cancer and found that "low-income women were only half as likely as higher-income women to have accommodating employers and only one-fourth as likely to retain their jobs."

Yet a September 2016 report by JAN,[6] based on interviews over the past twelve years with more than 2,000 employers in a range of industry sectors and sizes, showed that a majority of workplace changes cost nothing. The report found that 59 percent of the accommodations made for employees with a disability involved no direct cost to the employer. These accommodations included allowing an employee to bring a service animal to work or were the same benefits offered to nondisabled employees, such as flextime or telecommuting.

"Employees are accommodating members of their workforce all the time and don't think about it," says Susanne Bruyère, who directs Cornell University's K. Lisa Yang and Hock E. Tan Institute on Employment and Disability. An employer usually finds a way to accommodate someone who needs to leave early once a week to coach a soccer team, she explains, or will buy an ergonomic chair for someone with a bad back—even if that person doesn't have a formal medical diagnosis.

In fact, for many disability experts, especially those outside the United States, the preferred term is "workplace adjustment," not "special accommodation." The latter term implies a workplace change that occurs only because it is mandated by law, not because it is a generally accepted best business practice and, some might add, the right thing to do for any employee.

Even when a one-time expenditure is necessary, says Orslene, the typical cost is $500. "When employers can keep peo-

ple working, there are considerable benefits," he says, including avoiding the cost of hiring and training a new worker, improved employee productivity and attendance, and better overall company morale—according to JAN's report.[6]

A Rise In Chronic Disease

In 1900 pneumonia, tuberculosis, enteritis, and diphtheria caused one-third of all deaths in the United States, and 40 percent of those deaths were of children less than five years old.[7] A hundred years later, most Americans die of chronic diseases, which now account for seven of the top ten causes of death.[8] And half of those chronic disease deaths are caused by heart disease and cancer, which people may live with for years or even decades.

"Many women who live with metastatic or incurable breast cancer—it's certainly possible for five to ten years—continue to work and never spend a day in the hospital," says Lidia Schapira, an oncologist who is director of the Stanford Cancer Survivorship Program at the Stanford Medicine Cancer Institute.

The most common chronic conditions in adults—high blood pressure, which affects one in four people, and high cholesterol, which affects one in five—are unlikely to require extraordinary work accommodations: People with high blood pressure are sometimes advised not to lift heavy objects, and employees who are monitoring their cholesterol often need to make regular trips to the doctor.

But chronic diseases cover an enormous range of conditions, making each person's specific work travails unique. Many chronic diseases are rare or unusual, with rapidly evolving therapies. Other conditions, such as mental illnesses, are still stigmatized. Some result in near-constant pain, or the treatments—for example, chemotherapy—have side effects such as spinal problems, tinnitus, or the cognitive impairment known as "chemo-brain."

Other chronic diseases—such as Crohn's disease or the early stages of multiple sclerosis—usually lack overt symptoms but can have sudden exacerbations or flare-ups, which move a person very quickly from a steady state to an acute one.

Employees are most likely to tell their direct supervisors first about any chronic illness. But these front-line managers are typically specialists in workflow and productivity, not medical experts, and they can sometimes view the concept of an "accommodation" as a slippery slope that will soon encompass the whole workforce. "Most of the laws that employers deal with are about equal treatment," notes Linda Batiste, a principal consultant at JAN. "And accommodations are about doing something different."

The ultimate goals for business should be to remove hiring obstacles for anyone and to drop any assumption that a disability is an inherently compromising factor at work.

Managers may also worry that an employee might take advantage of medical time off by adding a couple of extra hours for something that has nothing to do with a trip to the doctor.

However, disability experts say that most employees are all too conscious of taking extra time off for medical appointments, even when the doctor visits are legitimate. Extended absences can hurt an employee's credibility at work, and the employee can be marked, if only informally, as an unpredictable or unreliable worker, explains Scott Trudeau, the Productive Aging and Collaborative Interprofessional Practice Program manager at the American Occupational Therapy Association.

Autumn Tupper, who sells insurance in the Dallas–Fort Worth area of Texas and was diagnosed with osteosarcoma in her left knee while in nursing school, struggles with extensive nerve pain and chronic exhaustion from her rounds of chemotherapy. She switched careers because "I knew I could no longer handle floor nursing, and this was a desk job with no heavy lifting."

Although her boss was understanding, he would text her if her follow-up scan appointments dragged into two or three hours. "Sometimes you can get in and out of your oncology office within fifteen minutes, but sometimes you're dealing with patients who are getting their diagnosis right before you," says Tupper. "When you're working in sales, and you're away from your desk, that's money they're not getting."

The pressure to justify medical visits away from the office, whether real or perceived, has kept Tupper from pursuing certain treatments.

"I need physical therapy. I'm not doing it," she says. "I don't want to risk losing my job for taking off that time. Is this really an absolutely necessary appointment? I don't want my boss to think I'm taking advantage of my time off."

Tough Questions Remain

JAN and a few other groups have created workplace accommodation tool kits[9] aimed at helping supervisors understand the concept of accommodation.

"That's one of the big goals of our tool kit—it speaks to the front-line managers," says Jennifer Hausman, director of the Public Health Program at the for-profit health insurer Anthem, which has produced its own tool kit in collaboration with Pfizer, Cancer and Careers, and the US Business Leadership Network.[10] "Take a customer service unit manager in a small satellite office who's twenty-one years old. Do they know the law? The majority of people are blown away by the fact that cancer is covered by the ADA."

But while the ADA does provide a legal bulwark against capricious firings or demotions of people with a chronic disease, that doesn't necessarily make employees' "decision to disclose" a chronic illness the obvious call, says Trudeau.

"Employees wonder 'Do I tell my employer I'm struggling with bipolar disorder and are they then going to walk around on eggshells? Do I tell them I need an accommodation? Or is it better if I buck it up?'" he says. "I tell them the truth. There is a difference between what's legal and what happens."

There's also the strategic question of when to disclose. Bob Carolla, a lawyer and senior writer at NAMI, the National Alliance on Mental Illness, who suffers from chronic depression, says it's important not to volunteer any information about a disability until there's an actual job offer on the table. "The best

circumstance," he adds, "is to disclose once you're three to six months into a job, when it's established that they like you and you are doing a good job."

With an aging workforce that will, by definition, include more and more employees with disabilities and chronic health issues, the ultimate goals for business should be to remove hiring obstacles for anyone and to drop any assumption that a disability is an inherently compromising factor at work, says Susan Scott-Parker, who runs the London-based nonprofit Business Disability International.

"Our job is to manage everyone's productivity," says Scott-Parker. "So instead of a recruiter getting distracted by a candidate with severe arthritis and asking, 'What can't you do?,' the right response is: 'Why don't we ask what we can do to make it easier?'" ■

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