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Being a Patient

Sick and Vulnerable, Workers Fear for Health and Their Jobs

By [LISA BELKIN](#)

When Marty Domitrovich was first told that he had [cancer](#), he was a 51-year-old sales executive, so successful that he had two goals: to reach \$1 million in commissions and bonuses and to become chief executive of his company, where he had worked since his summers in college.

Before long, however, he could no longer travel, and on the bad days he did his work at home, lying on the couch and talking on the telephone.

When Shannon Abert was first told she had scleroderma, she was 35, and loved her job teaching high school algebra. Until her illness was diagnosed, she was healthy and active, never taking a sick day from work, not even bothering to find a doctor who accepted her school district's insurance plan. Her disease progressed quickly, though, and soon she could not write on the blackboard, pull students' files or turn the classroom doorknob.

Work takes on many meanings when illness strikes: a cause of added stress; a place to escape from that stress; a source of income, insurance, identity and normalcy; and a fear of losing all those and more.

Both Mr. Domitrovich, now 58, and Ms. Abert, now 38, wanted to keep working after their conditions were diagnosed, and both asked their employers for help. One was told, "We'll give you whatever you need." The other recalls facing much more ambivalence, with one administrator telling her, "We all have problems, just do the job."

In this way, their stories reflect the realities of being ill in today's workplace, at a time when sick workers have more legal safeguards than ever before, and yet also face gaps, inconsistencies and question marks in those laws. Yes, how an employee is treated after crossing the stark line from worker to patient is broadly defined by legislation. But it is more specifically determined by things like the culture of a workplace and the sensitivity of a boss.

"We've come a million miles from the bad old days," said Robin Bond, who runs an employment law firm in Wayne, Pa., and represents individuals with claims against employers. "But no law changes the basic fact that employers want to do what's good for business. Their job is not necessarily to do what is good for you."

At a time when a worker is most physically and emotionally vulnerable, the person must also adroitly navigate to protect himself or herself.

"I didn't want to worry about work, but work was all I worried about," Ms. Abert said of the months after her illness was diagnosed in 2003. "I had to keep my insurance. I had to pay my rent.

"When you're sick," she said, "trying to get out of bed every day, that's the worst time to have to worry about your job, but you have no choice."

Double Jeopardy: Health and Job

Whether an employee enters a job with a diagnosed disability or becomes impaired after being hired, the worker faces the decision of whether and when to tell the employer. It is a choice loaded with emotion, and also with ramifications under the law.

"The diagnosis is a crisis in itself," said Carolyn Messner, an oncology social worker and director of education and training for cancer care in Manhattan. "The next crisis is telling people."

Mr. Domitrovich announced his devastating news almost immediately after he received it on Jan. 1, 2000. As vice president of sales and a regional manager for Cutco/Vector, which sells and manufactures cutlery, he was based in Chicago but traveled constantly.

When he began experiencing gastrointestinal symptoms in 1999, it was impossible to keep his team from noticing that something was wrong. He said he did try not to let word spread beyond that small group, however, because "as a leader you don't want to show too many of your weaknesses."

Soon the symptoms became more severe, and tests found an neuroendocrine islet cell [tumor](#) in the pancreas. The cancer had already spread to his liver.

Mr. Domitrovich told his wife and grown children first; then, within days, he informed the chief executive of the company and his close staff. The company's yearly banquet for the regional sales team was held two weeks later, and he shared the news in a brief speech to the 700 people who attended.

Ms. Abert, in contrast, kept her misery to herself. Her first symptoms appeared in the fall of 2002, when her fingers began turning purple, as if she had frostbite, but she knew that was unlikely in Clear Lake, Tex., near Houston.

An internist theorized that she had developed carpal tunnel syndrome from writing math equations on the board, and gave her wrist splints, which only made the problem worse. The pain spread to her legs and toes, but she did not tell her principal because she did not want to be seen as a weak link. It was stress, she reassured herself. It would go away.

It did not, and eventually, in January 2003, at the end of her school's winter vacation, a rheumatologist confirmed that Ms. Abert had scleroderma, a chronic connective tissue disease in which the body attacks itself, leading most noticeably to hardening of the skin. Now it was not pride, but fear and a need for privacy, that kept her quiet.

On the one hand, she was still absorbing all that was happening to her and she was not ready to share that exquisitely personal process with the world. At the same time, she did not know whether her job was in jeopardy and she was too afraid of the answer to ask the question. Besides, if her supervisors and colleagues knew, she was certain her students would find out as well, meaning she would lose the authority a teacher must have to command a classroom.

"I can't look at them and say, 'Y'all, I'm not feeling well,' " Ms. Abert said. "They will wreak havoc."

This instinct for privacy is common, said dozens of employees, employers, lawyers, health care providers and patient advocates interviewed for this article.

"I don't want to be labeled as the sick person, where all people see is the disease," says Tecela Harris, 38, who told only a version of the truth at a job interview for State Farm Insurance more than a decade ago, not mentioning that she had rheumatoid [arthritis](#), which made her joints swell horribly and caused constant pain.

"They told me the job was for claims adjuster and it included climbing up on roofs," Ms. Harris recalled. "When they asked, 'Are you going to be able to do that?' I said I could do it."

The result was years of agony until, needing to take 70 days off to recuperate from foot surgery to correct damage from the disease, she finally revealed her illness to her boss in 2000.

"I was almost in tears," during that conversation, said Ms. Harris, who is now on a recently approved medication that leaves her free of pain. "My illness was not something I was proud of, so I didn't really want to share that."

And yet, while patients might prefer to keep silent, the law favors disclosure.

Two pillars of legislation have come to define the rights of ill workers in recent years: the Americans With Disabilities Act, passed in 1990, requiring employers to make "reasonable" accommodations for disabled or seriously ill workers, as long as they can perform the "essential" functions of the job; and the Family and Medical Leave Act, passed in 1993, allowing workers to take up to three months off from work without losing their health insurance or job.

Under each, employers are only obligated to help employees whose conditions are known to them. A worker who regularly misses work for [chemotherapy](#) treatments, but does not

explain why, can be dismissed for absenteeism and cannot then appeal on grounds of disability.

That creates a dilemma that is equal parts emotional and tactical.

"I advise workers not to tell their employer, unless they want to ask for accommodation because of a disability," said Sharona Hoffman, a professor at Case Western Reserve University School of Law and an expert on the legislation. "If you want to invoke the protection of the law, then you have to tell."

A Plan to Stay Alive

Mr. Domitrovich armed himself for his early conversations with a business plan. He would never tackle a new business challenge without a plan, he said, and this was a new business challenge. Among his goals were to "stay alive long enough to find a cure" and to "see granddaughter go to grade school."

He told his bosses that he was certain he could keep working through his treatment, meeting sales projections. "I believe my team can produce, even though I'm not there every day," he remembers saying.

Sales positions at Cutco/Vector are paid solely on the basis of commissions and incentive bonuses, so his own income along with that of his staff was on the line.

For six months, Mr. Domitrovich was able to work with little trouble. The medication he was taking had few side effects and succeeded in restricting the growth of his tumor.

But eventually the mass began to press on his biliary duct, requiring surgery to insert a stent to relieve the pressure. Then the cancer began growing faster. He entered a clinical trial, which slowed the growth, but by then years of toxic medication had damaged his gallbladder, which had to be removed.

Through all this, he did meet his sales goals. His team's revenues increased 25 percent in 2001 and another 38 percent in 2002, which is the year he reached his \$1 million income goal. (He also saw his granddaughter start kindergarten last year.)

But the toll of work and treatment was heavy, and he decided that he could not keep up the pace.

Before Mr. Domitrovich could tell his bosses of that decision, though, they made one of their own. They announced a restructuring, increasing four sales regions to six, and effectively eliminating his job. They suggested another role that he might play: running the Fair and Show program, which coordinated cutlery sales at places like local fairs and conventions. It was an important part of the business, but it would require travel, which he knew he could not do.

When his disease was first diagnosed, Mr. Domitrovich joined a support group of cancer patients, and over the months, he said, he heard "the horror stories." The man with cancer of the jaw who had to take out a second and third mortgage on his home when he lost his job after his family medical leave time ran out. The man with stomach cancer who was told that his company would "stand behind you 100 percent," then let him go within six months.

So Mr. Domitrovich did not turn down the new job right away. Instead he asked for some time to think about what work he would like to do next.

'I Am So Sick, I Can't Make It'

Scleroderma patients have a particularly hard time getting out of bed in the morning, possibly because muscles stiffen and weaken overnight. Ms. Abert lived alone in the months after she became ill, and she had no one to help her with morning buttons and zippers. Each night she would take a sedative so she could sleep in spite of the pain, and even though she went to bed at 8 p.m., she was often late for the start of class at 7:30 a.m.

Her students noticed, she said, just as they noticed the [ulcers](#) on her fingers and the steady weakening of her hands. She could not get the caps off the markers for the dry erase board. Even screwing the top off a bottle of water meant asking a student for help.

But still Ms. Abert maintained the facade of health, until the fall of 2003, when the weather turned colder and she finally hit bottom.

It was the time of year when the forms arrived for her to choose her benefit options for the next 12 months. She read carefully, but when she found nothing about long-term disability, she assumed she did not have that option.

A search of the Internet found information about the Family Medical Leave Act, including the fact that the three months of leave were unpaid, and then neither her job nor her health insurance were protected.

She could not imagine how she would cope under those circumstances. Still, she thought, maybe a few months off would help her regain some energy. So she dragged herself to the human resources department, where she recalls telling a counselor, "I don't think I can do this anymore. I am so sick, I can't make it day to day."

His initial answer, she says, was: "You don't look sick. We're all tired. Hang in there."

"He kept saying 'It has to be measurable, you need documentation, it has to be something that can be measured,'" Ms. Abert said of Steven Austin, the director of employment benefits and risk management for the school district.

While Mr. Austin agreed that he probably did explain the need for documentation ("You have to provide certification for medical leave," he said in an interview), he said he did

not believe that he said anything harsher than that. He concedes, however, that others in the district may well have said such things to Ms. Abert.

"There wasn't a lot of support for her" from her superiors, Mr. Austin said, adding that he wondered whether her memory had put someone else's words in his mouth.

Most in Need, Most at Risk

The Catch-22 of the American health care system is that while many people work "for the insurance," when they become too sick to work and are most in need of that insurance, they are most at risk of losing it.

This is particularly true of workers at small companies, which are not covered by existing law. (The Family and Medical Leave Act, for instance, only applies to workplaces with 50 or more employees.)

One employee at such a company, who asked that her name not be used because she feared retribution from her former boss, learned the significance of this distinction the hard way when she had a brain tumor removed five years ago. Her employer, she said, "told me that my tumor came at a really bad time for the company."

The woman had recently received a significant raise, \$20,000. Her workplace was small - about a half-dozen employees - and a few months after her illness was diagnosed, the group's insurance premiums jumped. "My raise was rescinded, to cover the increase," she said.

Experts fear that as insurance rates increase, even companies large enough to be constrained by law will make personnel decisions based on the cost of health care. Those costs, which were stable during most of the 1990's, have increased at double-digit rates for the past three years, said Glenn Melnick, a professor of health economics at the University of Southern California.

Dr. Melnick thinks it is not coincidence that this environment led Wal-Mart, whose health costs increased 15 percent last year, to suggest what a confidential internal memorandum to the board of directors called "bold steps." If the company took action to "dissuade unhealthy people from coming to work at Wal-Mart," the widely leaked memorandum said, the potential savings would be \$220 million to \$670 million by 2011.

The proposed method of dissuasion, as explained in the memorandum, was to define every job so that it included some form of physical activity ("e.g., all cashiers do some cart gathering"). Unfit people would be less likely to apply and if they did apply, the company could legally refuse them because they could not do the job as described.

There is similar "wiggle room" in laws requiring employers to provide "reasonable accommodations" for employees, and here, too, experts are concerned. "The key word

when talking about accommodations is 'reasonable,' " said Ms. Bond, the employment lawyer. "And the employer gets to define that word."

If employers remain overwhelmed by health care costs, they may see this as an incentive to play hard ball, Ms. Bond and others fear, hoping that employees with health problems will just give up and go away, taking their expensive illnesses with them.

Navigating the Obstacle Course

Mr. Domitrovich suggested to his bosses that it was time that he left sales, stopped traveling and became a mentor. The result was "Cutco/Vector University," a management training program run by Mr. Domitrovich. His salary is only a fraction of his former commissions, but he maintains his insurance.

"We wanted to do whatever we could for Marty," said Bruce Goodman, chief executive for Vector sales and president of Vector West. "Marty is the conscience of our company."

Cutco/Vector might not be able to make similar arrangements for every ill employee, Mr. Goodman said, "but in Marty's case there truly was never any consideration of should we fire him, should we put him out to pasture."

Ms. Abert, in turn, tried to stay at work. She became vocal about her condition after her meeting with human resources, and she asked the maintenance staff to change the doorknobs on the teachers lounge and on her classroom so that she could open them more easily.

In the spring of last year, Ms. Abert's hands became seriously infected and she was hospitalized for much of the spring. Since then, she has been on long-term disability, which is a benefit available to every district employee, even though it was not in her packet of paperwork.

She will receive 80 percent of her income until she is 65, but she will not receive insurance indefinitely. Her district policy has already lapsed, and she will pay \$498 a month under COBRA until that too expires, next September.

Her unexpected ally in navigating the system was the same human resources counselor who seemed so brusque at their first meeting. "Once he saw I was really sick, he did everything he could to help," she said of Mr. Austin, to whom she now turns for advice.

Most recently, he told her not to return to teaching part time. If she did, the pay would be less than what she now receives on disability, though it would include insurance, making the equation temporarily worth it. But, he said, were she to require disability again, she would only be eligible for 80 percent of her part-time pay.

Ms. Abert has considered trying to return full time, but she cannot figure out a way to fit her regimen of doctor's appointments into a teaching schedule.

"I can't close the classroom door and say 'I will be back in an hour,' " she said. "It's difficult being sick as a teacher. I guess it's difficult being sick in any job."