

A Disability Doesn't Have to Force an Early Retirement

ROBYN DOCHTERMAN HAS OWNED A CHOCOLATE SHOP in Marine on St. Croix, Minn., since 2010 and has spent a lot of those 13 years putting chocolate in molds and flipping them out.

This repetitive motion has damaged her hands, and although she has had a few procedures and an operation to fix the problem, it keeps returning. For the past several years, Dochterman, 61, has been trying to figure out how she can keep working and manage her pain.

"I own my own business and if I had to be here till 2 a.m., no big deal," she says. "But now I have to dole out the hours to myself and make sure I don't overwork because I can't come back from that. It's a sort of asset management."

Many older workers are facing the same dilemma as Dochterman. Those 55 and over now make up 24% of the workforce, up from 12% 25 years ago, says Richard Johnson, a senior fellow at the Urban Institute think tank. According to a 2022 study in the journal *Research on Aging*, one in four workers who are still healthy in their mid-fifties will experience a disability in the next few years, making working more difficult. This includes both blue- and white-collar employees.

The disability can be caused by a sudden medical problem, such as a heart attack, a neurological disease such as Parkinson's, mental health challenges or, like Dochterman, chronic wear and tear.

The journal study also found that three-fourths of workers with new disabilities in their late fifties or early sixties left the workforce before full retirement age; that compares to one-third of those who didn't have a disability.

But many can't or don't want to give up their jobs. So how can they cope with their disability and continue working?

Support for Disabled Employees

Under the Americans with Disabilities Act, employers must provide "reasonable" accommodations to those with substantial impairments, which include problems hearing, seeing, speaking, breathing, performing manual tasks or caring for oneself. Reasonable is defined as not causing "undue hardship" for the company. Companies

with fewer than 15 employees, religious organizations and private clubs are exempt from the law's requirements.

Accommodations can include modifying equipment—even something as simple as a different chair, desk or keyboard—or changing work schedules or job restructuring. More information is available on the website of the U.S. Equal Employment Opportunity Commission (www.eeoc.gov).

Click on the tab for employees and job applicants and over on the right, under the section for "discrimination by type," select "disability."

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Working with Your Employer

About half of workers with disabilities receive accommodations from employers, Johnson says, but "a lot of people don't pursue it. To get accommodation, self-advocacy is really important. You have to be aggressive and pursue an accommodation with an employer."

One great boon for workers with disabilities has been the move toward remote work since COVID. That is true for Peter Winkelstein, 66, a pediatrician who suffers from a degenerative muscular disease called inclusion body myositis, for which there is no treatment.

Winkelstein, of Buffalo, N.Y., received the diagnosis when he was 60 and now walks with crutches; it is likely he will be in a wheelchair within 10 years. His hands are getting weaker, making it more difficult to type. He runs out of energy much sooner than he used to.

While the diagnosis was devastating, the timing was fortunate. Winkelstein had recently retired from clinical practice to become the chief medical informatics officer for Kaleida Health, the largest health system in western New York. He is also the executive director of the University at Buffalo Jacobs School of Medicine and Biomedical Science Institute for Healthcare Informatics.

"There's no way I could do clinical practice now," Winkelstein says.

Then COVID hit, and remote became the new norm. It stayed that way for Winkelstein after the pandemic waned.

"It takes me a long time to get ready in the morning, and although I can still drive, if I had to go in to work full-time, it would be really hard for me," he says.

Winkelstein decided to tell his human resources



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department early about his disability—before it was obvious—and was glad he did. He got support, and the company received information that, in certain circumstances, could be life-saving. For example, if there is a fire in the building, there is now a plan for how to get him out since he wouldn't be able to use the stairs.

No one is legally required to disclose a disability to their company unless requesting a workplace accommodation, says Ellen Dichner, a New York City labor lawyer. There are pros and cons to telling human resources, managers or colleagues about health challenges, experts say. Many people fear teasing or harassment, or that their coworkers and bosses will view them differently and that their career may stall.

When people can hide their disabilities—such as mental health issues—they often do, but that can become an emotional burden. Before his health challenge became obvious, Winkelstein says, he was reluctant to ask his colleagues for any kind of accommodation—even simply for a higher chair in a meeting room to make it easier for him to sit down and stand up.

But once it was more public, Winkelstein says, it proved a relief.

“You start discovering all the other people who have

invisible disabilities who want to talk to you,” Winkelstein says. “So it's kind of a mini-support network.” He has also started a general support group for inclusion body myositis in the upstate New York area, which has been very helpful, he says.

Trying to Keep Workers on the Job

Of course, some people want or need to leave their jobs due to their infirmities; this is often where Social Security Disability Insurance comes into play.

But there are numerous restrictions, and monthly payments average just \$1,489. If you are able to work, you can earn \$1,049 monthly on top of the disability payment, but most people don't work, Johnson says.

“The disability procedure is complicated and only half the people who apply are accepted on the first round,” he adds. “And because the process is so long, once people are on, they don't try to come off.” In other countries, he notes, people can be considered partially disabled and receive payments, but in the U.S. it is all or nothing.

The issue of keeping workers with health issues on the job is a major concern to both employees and employers; so much so that the U.S. Department of Labor's

Office of Disability Employment Policy launched a pilot program, RETAIN (Retaining Employment and Talent after Injury/Illness Network), in 2018 in a handful of states. The goal is to investigate early intervention strategies to ensure mid-career workers with disabilities can stay at or return to work.

One impetus for the program, says Yonatan Ben-Shalom, a principal researcher with the research and consulting organization Mathematica, is the lack of coordination between medical providers, employees and employers to ensure that as much as possible, people can return to work even with some sort of health problem.

A Challenge for Workers and Business Owners

While staying at a current job may be difficult in the long run for those with progressive disabilities, it's important to figure out what aspects of your occupation you enjoy and might be able to pursue in the future.

Winkelstein knows there will be a time when he will have to leave his present position, so he is taking a one-year course to earn a leadership coaching credential,

something he can see doing part-time and fully remote.

Since Dochterman, as a small business owner, is boss, employee and human resource department rolled into one, she has turned to a career coach for help

thinking through how to work with a disability.

The coach challenged Dochterman to work 20 hours a week for three or four months. Dochterman's usual work week is 50 hours, up to 70 hours during the holiday rush, which can last from December to May and includes Christmas, Hanukkah, Valentine's Day and Mother's Day.

She managed to scale down to 30 hours during the slower summer season and learned to say, "My thumb says 'enough.' I've got to go home."

As easy as this may appear, she says doing it was a challenge. "I cannot overstate how difficult it is to make that switch in my thinking."

She has one full-time employee and a few part-timers, and she says she is training them to help in more ways than in the past. "When you're a small business owner, it's pounded into you, you can do it all. But I can't hold that mindset anymore," she says. "Not only can I not do it all, but it would be a bad business decision to try to do it all. ■"

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What You Can Do If You Have a Disability

If you have any type of physical or mental health challenge that is affecting your work:

Research what your rights and options are. A good place to start is with the Job Accommodation Network (<https://askjan.org>). Go to the tab at the top labeled "individuals," and you'll find a wealth of resources about how, if and when to ask for accommodations as both a job seeker and employee. It also provides helpful information for employers that you can share.

Find out more about the federal Family and Medical Leave Act. With some restrictions, the law requires an

employer to give 12 weeks of unpaid leave for a serious health condition. Eleven states—California, Colorado, Connecticut, Delaware, Massachusetts, Maryland, New Jersey, New York, Oregon, Rhode Island and Washington—and the District of Columbia offer paid leave, and some companies do as well. For more information on the federal law, go to www.dol.gov/agencies/whd/fmla.

Weigh the pros and cons of informing your employer. Consider telling your human resources department or a trusted manager about your situation. Remember that hiding a disability can be an emotional as well as

a physical drain.

Find others in your situation. Joining an online or in-person support group for your particular disability can provide much-needed information and advice. Start one if one doesn't exist in your area. Peter Winkelstein, the pediatrician with the degenerative muscular disease inclusion body myositis, first called the The Myositis Association to ask if there was a support group in his geographical area. When he discovered there wasn't one, he asked if he could start one. The association offered him some training and support; he figured out the rest through his own research.