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Long Covid at Work: A Manager's Guide

It's time for organizations to be inclusive of employees with chronic illnesses. Here's how. **by Katie Bach, Ludmila N. Praslova, and Beth Pollack**

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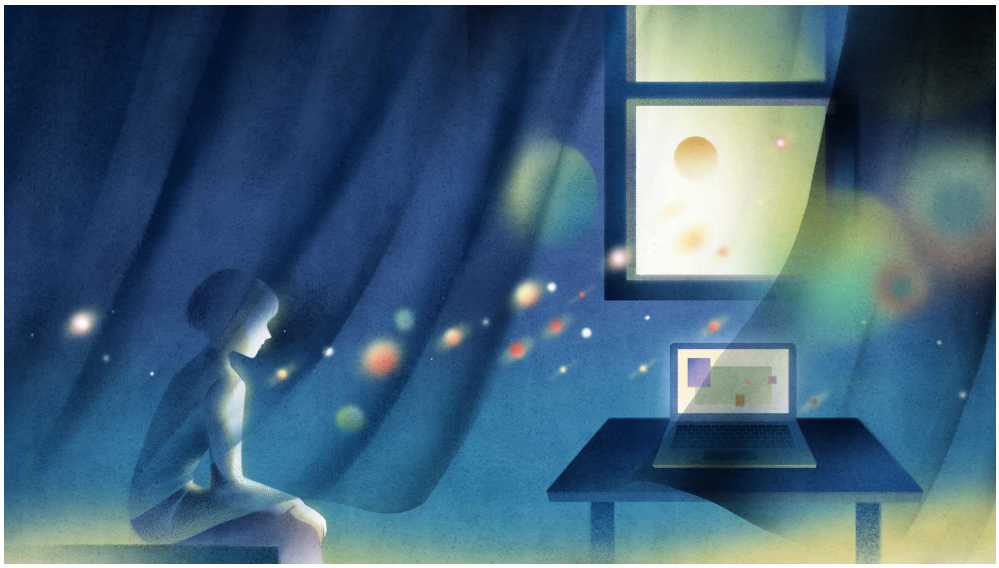

Jasu Hu

Before the pandemic, Dara was a research engineer, thriving in a job that involved complex technical design and problem-solving. (Names in this article have been changed for privacy.) She was also an avid baker and a voracious reader. Then in March 2020, she got Covid-19. Even after the acute illness had passed, many symptoms remained: Dara struggled to sit up for more than half an hour, was too breathless and lightheaded to walk even short distances, and had severe brain fog that left her unable to hold a conversation or write an email. She used all of her paid

and unpaid leave to rest and try to recover. Eventually she improved enough to return to work — but she knew her job needed to change.

Collaborating with her managers and the HR team, Dara found a set of accommodations that fit her needs. They gave her the option to work from home whenever she wanted — up to 100% of the time and at a reduced schedule. For days when she wanted to go in to the office, they secured a mobility scooter to help her get around the building. She also received additional unpaid leave to manage symptom flares. "I wouldn't still have a job without [that] support," Dara says.

As her health has improved, she's been working with her managers and HR to resume her career growth. She was recently promoted to a role with more managerial responsibilities.

Dara's story, for all its challenges, is a hopeful one. However, many other people's experiences of trying to work with long Covid are not.

Annette was a researcher at a large university prior to the crisis. She worked long hours and felt well respected in her department, which she'd been in for seven years. She commuted nine miles a day on a bike and was a mountain climber outside of work.

Then at age 30, during the height of the pandemic, Annette was left with debilitating symptoms, possibly due to asymptomatic Covid. She struggled with basic mobility and overwhelming exhaustion, and was eventually diagnosed with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and postural orthostatic tachycardia syndrome (POTS): chronic illnesses that people with long Covid commonly develop.

Once Annette's department returned to the office, management required her to come in four days a week, even though the three days that were standard for her colleagues would have been sufficient for her particular job tasks. When she approached her supervisor, she explains, "I asked for nothing but two days a week at home like everyone else had, because I desperately needed…the bandwidth to figure out what was happening to me." Her boss referred her to HR, who sent her back to her boss. "I went around in circles like that for a while," Annette says.

Eventually her request was denied. She was told to use sick days if she couldn't come in. But after speaking with HR, Annette was left with the impression that she might be penalized if she took too many days off, even though the department had a policy of unlimited sick time. Annette told HR that she was going to raise her concerns with the university's disabilities office, and HR made it clear that they would contest her account.

Just as Annette was getting desperate, another university offered her a more administrative-based job. It was a step down in terms of responsibility and pay and meant leaving the research field she loved, but it came with a truly hybrid schedule. With more flexibility, Annette could focus on improving her health, though she still grieves the loss of her previous career.

Unfortunately, for most people with chronic illnesses, and especially for long Covid patients, Annette's experience is more common than Dara's. One of us, Katie, recently surveyed more than 850 people with long Covid to understand their experiences at work. While many respondents cited accommodations as the reason they could keep working, others said they were scared to ask for any or weren't given an opportunity to. Comments included:

- "I was on short-term disability when I was let go."
- "I was still in the hospital when I was fired, still trying to recover from Covid."
- "As it was 2020, no one believed me about long Covid, and I was treated like it was all in my head."
- "Due to the stigma, I was scared to pursue accommodations."

Dr. Ilene Ruhoy, a neurologist specializing in long Covid and complex chronic illness at the Mount Sinai Health System in New York, is familiar with such stories. She says that many of her patients have lost their careers due to their employers' failure to accommodate chronic illness and that it has left many of them feeling hopeless.

On the flip side, as stories like Dara's show, the right workplace support can be transformative. Employers must not only help these individual employees but also build disability inclusion into their cultures and talent practices.

Companies Have a Long Covid Problem

As of March 2024, 6.9% of U.S. adults — 17.8 million people — have long Covid, a multisystem illness that sometimes appears after bouts of Covid-19. Its wide range of symptoms vary from person to person, range from mild to severe, and can wax and wane over time. The most common include severe fatigue, post-exertional malaise (PEM, a worsening of symptoms after physical or cognitive exertion), cognitive impairment (such as problems with memory, focus, or comprehension), pain, and neurological and sleep issues. Long Covid disproportionately impacts women — about 63% of patients are female. There are no official treatments for the illness; while some people see their symptoms resolve, others remain chronically ill.

In January 2022 Katie was one of the first researchers to link long Covid disability with a worsening labor shortage. Later that year she and David Cutler, a professor of applied economics at Harvard University, estimated that long Covid costs the U.S. economy between $160 billion and $200 billion per year in lost wages and increased medical costs. In May 2023 the Brookings Institution reported that 700,000 people were absent from the U.S. labor force due to the illness. Some of these people may be too sick to work, even with accommodations.

Yet 65% of adults with the illness are still working — in some cases for fewer hours, or while struggling with tasks that used to be easy for them, or both. Even if they don't realize it, many employers have a long Covid problem, making it more challenging to hire and retain employees and to support their productivity.

While the focus of this article is long Covid, the recommendations here can help organizations manage the growing number of people with complex chronic illnesses. These include not only ones associated with long Covid, such as ME/CFS and POTS, but also other illnesses that share some symptoms with long Covid — for example, post-concussion syndrome, cancer, and multiple sclerosis.

As employers consider how to provide and customize accommodations, they need to be aware that it is often challenging for employees with these illnesses to get medical documentation or even a diagnosis. There are too few clinicians who specialize in them, nonspecialists may be less familiar with them, and underdiagnosis is common. For example, pre-pandemic it was estimated that 84% to 91% of people with ME/CFS weren't diagnosed. Dara, from our first example, saw five doctors over four months during her early stages of long Covid but couldn't get one to provide documentation to her employer. Thankfully, her HR

department recognized how ill she was and was willing and able to accommodate her needs; Annette can attest that's not always the case.

Accommodations Must Deliver Flexibility

For your organization to start supporting people with long Covid and associated conditions, it's important to first understand how people experience the different symptoms.

The fatigue that people with long Covid and similar conditions experience has little in common with normal, day-to-day tiredness or weariness. This fatigue is physically crushing. As one respondent from Katie's survey said, echoing a sentiment shared by many: "[I] am now a shadow of myself. I'm completely isolated due to the fatigue."

Their fatigue is severe, multifaceted, and persistent, and it happens at a cellular level. In people with ME/CFS and also many with long Covid, the function of the mitochondria — the cell powerhouses that create energy — is impaired, and there are physiological changes in these patients after exertion.

When people with long Covid exceed their energy capacity, symptoms can often worsen, sometimes severely, as with PEM. Those in chronic illness communities often describe this phenomenon using the "spoon theory." Imagine that every exertion costs you a spoon of energy. Taking the subway to work? Fifteen spoons. Sitting upright at your desk or attending a meeting? Ten spoons. While a healthy person may have unlimited spoons to use, people with complex chronic illnesses often have a finite number. Importantly, patients with severe illness may have very few to almost no spoons, whereas patients with mild illness have more. However, if they exceed their allotment, their symptoms flare.

Flares can be significant, leaving some people bedbound for days or weeks. What makes these illnesses even more confusing is that energy capacities vary, as does the extent to which specific activities are draining, even for the same person. For example, someone with long Covid might have five spoons one day and 15 the next, or 10 spoons in the morning and only three in the afternoon.

Because long Covid and similar conditions are complex and dynamic, we recommend that accommodations be customizable and designed for flexibility. There is no one-size-fits-all approach — sometimes not even for the same employee over time, which can be challenging for employers to understand and manage. The good news is that by adjusting *how, where,* and *when* people do their work, it's possible to respond to the symptoms that are most problematic (and "spoon-draining") for any given worker.

We advise starting with a menu of options and then customizing from there. For example, if an employee experiences extreme fatigue, energy fluctuations, or post-exertional malaise, accommodations might include flexible work hours, part-time options, opportunities for daytime rest, remote or hybrid work, and the ability to organize work priorities around energy windows (i.e., "spoon planning"). For cognitive difficulties or brain fog — other common symptoms — employees may benefit from accommodations such as task reminders, written instructions, quieter workspaces to reduce distractions, asynchronous work opportunities, flexible hours, and recordings and transcripts of meetings they can reference. (A list of 10 common symptoms and potential accommodations can be found at the end of this article.)

Supporting people with these conditions also means reviewing and potentially adjusting the work they are asked to do. Is there room to

reassign tasks that are particularly challenging for an individual and to add in tasks better aligned with their current capacity?

Consider recruiters, who may do a combination of on-site work (such as job fairs and hiring days at specific locations) and remote work that can fit schedule needs (such as reviewing résumés, screening candidates over the phone, and talking to colleagues across departments to understand hiring needs). If a recruiter with long Covid has significantly more cognitive energy than physical stamina, for example, could they take on additional remote work in lieu of on-site tasks?

Inclusion Must Be Built In

A menu of accommodations along with individual job redesign efforts will help employers retain employees with long Covid and other chronic illnesses and enable these workers to contribute more than they could otherwise. But organizations that take a more comprehensive approach — building inclusion into the entire talent cycle, as explained in Ludmila's book, *The Canary Code* — will have the true advantage in hiring, retention, and productivity across their workforces.

Here are some recommendations. Many are best suited to office jobs, but some can also be used to support frontline workers (e.g., food and beverage services, retail, nursing, etc.). Employers that need to find accommodations for frontline workers may want to focus on providing robust short- and long-term disability coverage and flexible leave-of-absence policies. In addition, consider retraining those employees for less physically demanding roles, if possible.

Recruitment. Make sure job descriptions focus on essential job functions. Do not include physical requirements for tasks that may need to be performed only on rare occasions. For example, requiring

someone to lift 20 pounds "just in case it's ever needed" is both unnecessary and potentially discriminatory.

Candidate assessment. Exclude demands from the hiring process that aren't essential to the position. For example, don't make an interview day an endurance test unless that mimics the conditions of the job.

Onboarding and team-building activities. Avoid bonding exercises that are physically or mentally taxing in favor of inclusive options. Try swapping the obstacle course or the group yoga class with an icebreaker that works for everyone, like asking people in advance to come up with a six-word title for their autobiography and to be ready to share with the group.

Work organization. This is crucial to providing flexibility. Most flexibility-focused interventions are free and provide a great benefit to all employees — but they're critical for allowing disabled, chronically ill, and neurodivergent talent to participate in the workforce. Consider:

- **Remote-work options.** When roles can be performed remotely, even partially — for example, among call-center employees — this option can be a significant accommodation.
- **Flexible hours and/or scheduling.** Be open to different employees working different hours, with mutually agreed overlap. This can pay off for everyone: Employees with long Covid or similar chronic illnesses can work at the times of day when they're most alert, and their peers get more flexibility for things like childcare and other day-to-day responsibilities. Even in roles with fixed hours, employers can offer more flexible scheduling options. This could include allowing for later start times, longer breaks, or part-time hours to accommodate energy fluctuations and medical appointments, or

enabling employees to swap shifts with their colleagues (a practice that workers resoundingly appreciate).

- **Efficient work processes and tools.** Let employees align their work with their energy levels by providing asynchronous collaboration tools and minimizing unnecessary meetings. Ask people what would make work easier for them — for example, having access to work-related phone apps that can be used while lying down.

Workplace design. Inexpensive adjustments to the physical workspace can make a significant difference. These could include:

- **Improving indoor air quality.** Better filtration or windows that can be opened are useful here.
- **Providing seating for roles typically performed standing.** Cashiers, for instance, do not need to stand. In an office or a factory, you might have a room with a couch, pillows, and/or a yoga mat that employees can easily reserve for breaks.
- **Offering basic resources.** Ensure easy access to hydration, restrooms, and quiet rest areas.
- **Accommodating limited "uptime."** Some people with long Covid struggle with uptime: They're able to stand or sit for a limited number of hours (or even minutes in some cases) but may be able to work for hours lying down. When it's possible to offer in-office supine workstations or rooms where employees can meditate or nap, that may be an effective accommodation; when it's not, companies should consider allowing partial or total remote work.

Skill development and training. Provide training options that accommodate energy and symptom fluctuations. Lengthy in-person sessions can be exhausting, but so can ones that require sitting for hours or progressing at a set pace. Flexible learning will include options for in-person, video, or text-based work, allowing participants to control the length and speed of sessions. Do not use "time spent" or "pace"

as a proxy for success. Instead, test skill acquisition or information comprehension directly.

Inclusive norms. Leaders should establish and role-model flexible and accommodating behaviors. For example, in hybrid meetings, while in-person employees might be sitting upright on camera, make sure those who are sick and working from home feel comfortable lying down on camera or not being on camera at all. Use the raise-hand feature to ensure that everyone can speak.

Employee inclusion training. Train managers and HR on nonapparent disability inclusion. Complex chronic illnesses are frequently misunderstood, so one option is to invite speakers with lived experience to educate others.

Job redesign or task modification. Where possible, adjust the duties of a role to fit the current capabilities of an employee with long Covid — such as by shifting them from a physically demanding task to a less strenuous one.

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There is encouraging clinical and research momentum for long Covid and related conditions. In a congressional meeting in January, U.S. senators on both sides of the aisle called for more funding to support medical research. Advocates from multiple organizations associated with chronic illnesses, including long Covid and ME/CFS, are lobbying to create a new government office to support a coordinated approach to researching these illnesses. And scientists are actively studying long Covid mechanisms and trying to identify potential treatments. (Among those scientists is one of us, Beth, who studies shared features of complex chronic illnesses and is working on a clinical study of long Covid and chronic illness at MIT.)

The Job Accommodation Network reports that workplace accommodations cost nothing for more than half of employers, and when there is a cost it tends to be onetime and around $300. Yet stories from the many people whose careers and lives have been derailed by long Covid and associated chronic conditions — and in some cases by a lack of understanding from managers, HR, and coworkers — show that our society has a long way to go in helping people with complex chronic illnesses.

When we fail to offer sufficient support, we're not just failing people with these illnesses — we're failing society, all of us. We're depriving our economy of the expertise, experience, and perspectives of millions, and we're failing to create systems where all talent can thrive. Providing the right accommodations for people with chronic illnesses is a human and economic imperative.

10 Common Symptoms of Long Covid and Associated Chronic Illnesses

And potential workplace accommodations for each.

Symptom	Accommodations
Extreme fatigue, energy fluctuations, and post-exertional malaise	• Flexible work hours • Part-time work options • Opportunities for daytime rest • Remote or hybrid work • Letting people organize work priorities around their personal energy windows ("spoon planning")

Cognitive difficulties, cognitive fatigue, and brain fog	• Task reminders • Written instructions • Quiet workspaces to reduce distractions • Asynchronous work • Flexible hours to enable work in higher-energy periods • Project assignments that avoid urgent deadlines • Recording meetings and/or getting transcripts for future reference
Challenges being upright (such as dizziness, loss of balance, and fainting)	• Remote-work options • Options and equipment to work while sitting (e.g., a chair for a cashier) or supine (e.g., a work phone with access to email and internal systems, a zero-gravity chair, or a computer stand that allows the computer to be positioned over someone who is lying down)
Sleep issues (insomnia, unrefreshing and poor-quality sleep, sleep apnea, and circadian rhythm problems)	• Flexible work hours • Asynchronous work • Allowing individual employees to join meetings or schedule shifts within preferred windows
Mobility limitations and neuromuscular dysfunction	• Providing mobility aids and assistive devices (e.g., tools that help someone reach and grip items, joint and back supports, wheeled bags, walkers, canes, and scooters) • Ensuring that workspaces allow for mobility aids and assistive devices
Gastrointestinal and urinary symptoms	• Frequent bathroom breaks • Allergy- and sensitivity-friendly food options at group events • Accessible bathrooms • Remote work
Reproductive health issues	• Flexible work times, in particular around the menstrual cycle and during pregnancy and menopause, when chronic illness symptoms can be exacerbated

Chronic pain (including but not limited to headaches and joint, muscle, and chest pain)	• For photosensitivity, allowing employees to wear sunglasses or blue-light-blocking glasses; providing screen-glare reduction tools such as software or screen protectors; keeping overhead lighting lower and adjustable; allowing cameras to be off in meetings • For sound sensitivity, offering quiet workspaces or providing earplugs or noise-canceling headphones • Talk-to-text software to replace typing • Ergonomic workstation setups • Mobility devices to use in the office • Letting employees work in the physical position most comfortable to them (e.g., reclining, supine, or sitting up, with supports like pillows or braces)
Respiratory issues, increased allergies, and environmental sensitivities	• Improved office ventilation and air filtration (e.g., open windows, HEPA filters, air quality sensors) • Allowing employees to wear a mask of their choosing at work • Using unscented, nontoxic, and zero-fragrance cleaning products • Creating no-fragrance office policies, or asking employees not to wear scented products • Inspecting the office for mold or water damage • Using no-VOC (volatile organic compound) paints and materials in the office
The need to avoid infectious illness (Covid or otherwise)	• Offering remote-work options for immunocompromised or vulnerable employees • Allowing employees to wear a mask of their choosing at work • Improving office ventilation and air filtration (e.g., open windows, HEPA filters)

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Katie Bach works with companies to improve job quality and employee experience. She has written extensively about the labor market impact of long Covid, including as a former nonresident senior fellow at the Brookings Institution, and serves as board chair of PolyBio Research Foundation, which focuses on complex chronic conditions. Follow her on LinkedIn.

𝕏 @kathrynsbach

Ludmila N. Praslova, PhD, SHRM-SCP, uses her extensive experience with neurodiversity and global and cultural inclusion to help create talent-rich workplaces. The author of *The Canary Code,* she is a professor of graduate industrial-organizational psychology and the accreditation liaison officer at Vanguard University of Southern California. Follow Ludmila on LinkedIn.

Beth Pollack is a research scientist at MIT. She studies long Covid and associated illnesses and leads research on their overlaps and shared pathophysiology in MIT's Tal Research Group. Beth is the chair of the ME/CFS Less Studied Pathologies Subgroup and a member of the ME/CFS Research Roadmap Working Group at the National Institutes of Health, working to create a national plan to advance research on the illness toward clinical trials. Currently collaborating on three clinical studies on long Covid and associated chronic illnesses, she is a member of the Patient-Led Research Collaborative and a former senior researcher at Harvard University. Follow Beth on LinkedIn.

How to Weigh the Risks of Disclosing a Disability

A guide to help you decide — and find support. **by Ludmila N. Praslova**

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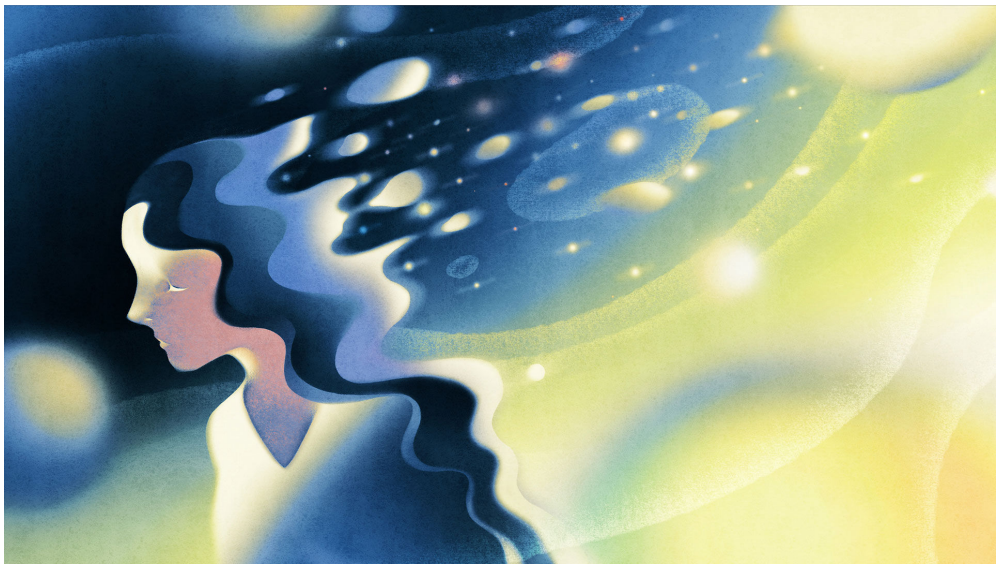

Jasu Hu

Whether to disclose your long Covid, or any other nonapparent condition or disability, to your employer is a deeply personal and consequential decision. While disclosing may help you access accommodations, it carries risks stemming from stigma and ableism. You might get support, but you might also be met with suspicion, resentment, and accusations of making it all up.

Consider a composite case study. Ali developed long Covid while working at an international consulting company. He worried about

disclosing it at work, but symptoms including extreme fatigue and dizziness were interfering with his travel for in-person projects. He eventually confided in the department head, who made accommodations, assigning Ali to remote consulting and research projects.

However, even though Ali contributed extra work and ensured his output was impeccable, coworkers began to make snide remarks, perhaps resenting that they had to travel while he did not. When a new department head came in, colleagues upped their complaints about Ali being a "flake," and when he disclosed his illness to the new manager, he was met with a suspicion of faking it. The additional stress caused Ali's health issues to flare and he was ultimately forced to resign.

Unfortunately, research indicates it's not rare for a disability disclosure to lead to accusations of faking and other negative attitudes, both conscious and unconscious. Many studies have also documented high rates of workplace bullying and stigmatization of disabled people. (Note: disability communities generally favor identity-first language.)

As an autistic woman (misdiagnosed, like many, with depression for much of my life), I've navigated various disclosure options and fear of mental health stigma for over 25 years while also encountering additional, more physical challenges. In most work settings I haven't disclosed or asked for accommodations, relying instead on job matching and job crafting to use my strengths to excel. Successful matching meant that I faced misalignment between my work and abilities only when responsibilities far outside of my job description — or other surprises, like office moves — were thrown my way. When that happened, I found work-arounds. I did, however, lose career opportunities — my sensory sensitivities make noise and artificial lighting debilitating, so I've had to turn down otherwise excellent job

offers that didn't come with access to quiet space, natural light, or hybrid work.

When I do disclose my health needs, most people are considerate, but some have laughed in my face, dismissed the information, or even used it against me. I've learned many lessons the hard way, and over time stopped trying to blend in and have become increasingly open. In the last several years this "radical disclosing" has taken the form of autism, neuroinclusion, and disability advocacy via social media. I write on topics of neurodiversity and disability at work in both academic and general forums.

In this article I'll discuss why disclosure is a risk, how to decide whether it's one worth taking, and how a network of supporters at work can help you minimize the potential downsides.

Deciding Whether to Disclose

Unfortunately, disclosing a disability or neurodivergence information is often a "damned if you do, damned if you don't" situation. Research shows that 61% of disabled employees have experienced some form of workplace discrimination, including hiring biases, pay gaps, bullying, and mistreatment. And when people with nonapparent conditions share their struggles, they often get a "You look fine" response, adding to their reluctance to disclose.

Ableism, or the belief that a disability makes a person inferior to or less valuable than others, can lead to discrimination and exclusion. While hostile ableism manifests in rude treatment and bullying, benevolent ableism — a form of paternalistic bias — may result in people limiting others' opportunities for participation and professional development to "protect" them. For example, the boss of a disabled employee may assume the person will face resentment if promoted, and withhold

information about leadership development opportunities "for their own good" — taking away the employee's choice. Regardless of motivation, both hostile and benevolent ableism can undermine a person's career.

Legislation such as the United States' Americans with Disabilities Act (ADA), Australia's Disability Discrimination Act 1992, and other countries' equivalents can somewhat protect a disabled employee from blatant discrimination, such as being fired specifically because of their condition. But it does not prevent more insidious forms of mistreatment, such as gossip, social exclusion, being assigned an impossible workload, or being excluded from professional development and advancement opportunities.

How can you determine whether it makes sense to disclose your condition at work? Here are the key steps.

Clarify your priorities. Disclosure involves many uncertainties since you can't control others' reactions and biases. Rather than attempting to predict how people will feel, tie your decision-making to your personal guiding principles. To start, figure out your nonnegotiable needs for your health and well-being. A few questions can help:

1. **What are the health risks?** Ask yourself, "Is continuing to work without necessary accommodations risking my health, safety, or energy levels?"
2. **What are the career risks?** Ask, "What's the worst that could happen if I face ableism, and how does it compare to the potential risks of not advocating for my needs?"
3. **What are your essential needs?** Ask, "What's core to my survival and to maintaining a basic quality of life?"

Once you've identified your key needs, look for alternative ways to meet them in case your work situation does not improve or your disclosure

backfires. Ask yourself, "What other sources of support or earnings have I not considered?" This could involve exploring job roles with the necessary accommodations or alternative income sources.

It's hard to see all the options when you're stressed; a friend, a family member, or a trusted colleague can provide new perspectives. Ask them, "Can you see alternative solutions I might have missed?" or "How would you approach this situation?"

Weigh the pros and cons of disclosure. With your priorities and backup plan in mind, consider the pros and cons of disclosing your condition in your current job. Here are some typical ones; the odds of specific outcomes may depend on organizational culture and power holders.

Pros:

- Legal protection from blatant discrimination
- Opportunity to openly discuss health-related needs and proactively manage symptoms
- Access to accommodations
- Potential for a supportive workplace environment
- Potentially higher likelihood of maintaining employment

Cons:

- Risk of stigma and subtler forms of discrimination and exclusion
- Privacy concerns about medical information
- Coworker envy, resentment, and bullying in response to accommodations
- Uncertainty about how disclosure will be received
- Potential bias from supervisors or coworkers
- Potentially lower likelihood of advancement
- Possible obstacles to professional development

Consider your timing. There are also pros and cons to *when* to disclose. For example, while job candidates are not required to disclose during the hiring process, many hiring managers feel affronted by a lack of disclosure. And yet many hiring managers also discriminate against disabled applicants.

There is no one-size-fits-all advice here. Many people believe that disclosing early allows them to live according to their values and to filter out organizations that might be a poor fit. At the same time, others lack the economic safety net to allow for a prolonged job search.

Think about these factors for different timing options:

In the application or cover letter:

- **Pros:** Allows the employer to prepare for accommodations
- **Cons:** May harm your chances of getting to demonstrate your capabilities and be hired

During the hiring process:

- **Pros:** Gives you an opportunity to address questions about your condition
- **Cons:** Risks drawing attention away from your strengths and abilities; risks lowering your chances of getting the position

After getting an offer or being hired, but before beginning work:

- **Pros:** Possibly provides you with legal recourse if the hiring decision changes unjustly
- **Cons:** Employer may distrust you for not disclosing earlier

After beginning work:

- **Pros:** Gives you an opportunity to establish your competence before disclosing
- **Cons:** May cause you anxiety about your ability to perform without accommodations; potentially harms your health due to working

without needed accommodations; employer potentially has a negative reaction to the delayed disclosure

After a problem arises, when new job requirements are introduced, or when your need for accommodations becomes clear:

- **Pros:** Gives you an opportunity to prove your capabilities before disclosing
- **Cons:** Potentially harms your health due to working without needed accommodations; employer potentially has a negative reaction to the delayed disclosure

Never:

- **Pros:** Reduces the risk of discrimination based on stigma
- **Cons:** Increases your risk of being fired or suffering other adverse actions if your disability impacts your performance; potentially harms your health due to working without needed accommodations

Your decision about timing may depend on the extent of your need for accommodations and whether you have the resources to continue a job search until you find a disability-inclusive company. Your desire to help normalize disability and disclosure may also come into play.

But what if you develop health issues while employed and need to disclose, but are worried about the employer's lack of understanding? The next strategy can help reduce the risks.

Creating a Network of Disclosure

People often want to disclose just to one person — maybe their supervisor or someone in HR — and only if they must. But as Ali's story earlier in the article illustrates, having limited support can backfire. What happens if that person leaves your team or company?

Creating a network of disclosure — in other words, disclosing your condition to two or more people — can be a part of the solution, though it may sound counterintuitive. After all, doesn't it increase your chances of experiencing bias? Possibly, but it can also increase the chances you'll get the support you need, and research shows that people who make a commitment known to others are more likely to keep that commitment. If your accommodations are discussed with your manager, HR, and the accessibility officer, any one party will have a harder time going back on their word.

Caution is advisable because it's not always possible to predict how people will react to your disclosure. Your friendly supervisor may end up showing a cold and suspicious side, but a gruff coworker could turn into your staunchest champion. So, much like when you took stock of your guiding priorities, start with the basics. Consider your organization's overall culture and standard procedures. Are there policies or practices in place to assist disabled employees? Are there any examples of people who received help for health issues? If so, can you find out which units and individuals were most considerate of them?

Then, decide who to reach out to. Here are the people and groups you might look to for support, albeit with downsides for some:

Your manager. Disclosing your health challenges allows your manager to better understand your needs and provide accommodations that contribute to your well-being and productivity. These could include flexible work arrangements, aligning your assignments and tasks with your abilities, or access to assistive technology. Disclosure could also help build trust and open the door for better communication. In most cases, it's important to have your manager as part of your disclosure network. That said, not all managers are equipped to support employee

disability needs; this is why a network of other potential advocates might be necessary.

Human resources. Discussing your health challenges with HR usually maximizes the likelihood that your rights under disability laws like the ADA will be protected. In many organizations, HR is best positioned to provide guidance on available accommodations and resources. Unfortunately, in others HR accommodation procedures are extremely difficult to navigate; getting assistance from some of the offices below might be useful.

Accessibility office. At some organizations, ensuring that work environments meet employees' needs is the responsibility of a separate office. The accessibility office or officer can help you navigate the accommodation process, ensure that your needs are addressed promptly and effectively, and provide resources and guidance.

DEI or DEIA offices. While disability is not always prominent among DEI (diversity, equity, and inclusion) initiatives, it is a form of diversity, and disability inclusion is a DEI responsibility. The DEI team can serve as an advocate and ally to promote your well-being and professional growth. This is particularly likely if your DEI office is explicitly responsible for "A," the accessibility part of DEIA.

Coworkers. Disclosing your health challenges to at least some of your colleagues allows them to understand any accommodations or adjustments you may need, and this understanding may help them develop a more empathetic perspective. Sharing your experiences with coworkers can also create a network of allies who can offer support when needed.

Disability employee resource group. An employee resource group (ERG) can connect you with a community of peers who understand your experiences and can offer empathy, guidance, and encouragement. It provides a safe space to share your concerns; work through any feelings of anxiety, self-doubt, or shame associated with internalized ableism; and develop a positive identity around disability, chronic illness, or neurodivergence. Some ERGs also help organizational leadership improve accessibility and accommodation processes and otherwise advocate for inclusion.

Outside disability organizations. These can range from national to local, and from formal associations to informal groups. Participating in them can validate your experiences, help you feel less alone, and provide many practical tips. For example, the American Lung Association has online mutual care communities, including one for long Covid, and the Long Covid Alliance provides links to a variety of support groups.

Having the backing of your manager, HR, an ERG, and/or multiple colleagues can provide a much stronger foundation for building a positive work environment despite your health challenges. In some cases you may also consider a "radical" disclosure (such as educating colleagues about your condition in a meeting, explaining how it impacts your communication in your email signature, or "coming out" via social media) to both live out your authentic identity at work and help reduce the stigma surrounding health differences. While not without risk, radical disclosure can expand your network in ways that prevent the potentially catastrophic consequences of losing a sole supporter.

Focus on Strengths

If you decide to disclose a medical condition or a disability, the next step often involves working with your manager, team, or organization

to develop a strengths-based plan for your work. The plan should be tailored to what you do best and what you can do well regardless of health challenges.

A comprehensive flexibility framework that I created suggests aligning *what* people do with their strengths and *how* they do it with their health needs and energy levels. Rather than focusing on deficits, this approach calls for focusing on what people can do (for example, working on project planning versus attending client meetings, or negotiating over the phone versus doing it in person). Here's what comprehensive flexibility might look like when applied to a dynamic disability such as long Covid or many mental health conditions:

1. Identify the individual's strengths and what they can do with or without accommodations.
2. Match their strengths to specific tasks and responsibilities.
3. Ensure access to professional development, accommodations, or tools as needed.
4. Provide maximum flexibility in how and when the work is done.
5. Evaluate, reassess, and adjust as needed.

A version of this approach can even be used by entrepreneurs or self-employed people who are managing themselves. Some adjustments might be more substantial than others, but a strengths-based, flexible approach to work can be a foundation for building a rewarding and productive career even while dealing with health challenges.

Of course, organizations have an important role in helping all talent thrive. Principles for developing flexible organizations and examples of effectively overcoming barriers to disability inclusion are described in more detail in my HBR article "The Radical Promise of Truly Flexible Work" and my book, *The Canary Code: A Guide to Neurodiversity, Dignity, and Intersectional Belonging at Work*.

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I'm still fine-tuning my own approach to disclosure. As of this writing my neurodivergence is radically shared with the world, but with more-physical differences I am using a network of disclosure at work. Both strategies seem to be working much better than the "quietly pushing through" approach, which on several occasions has led me to the dangerous extreme of overworking while trying to prove myself. They also work better than disclosing only to a supervisor.

You may follow a similar path, or you may not. Disclosure decisions are deeply personal. But it's important for all of us to remember: Our worth and human dignity far surpass our ability to perform specific tasks. The responsibility for ableist behavior lies on those who exhibit it — not on us. Our health should come before having to prove ourselves to others. Advocating for inclusive workplaces isn't just about securing accommodations; it's about creating organizations where every person is valued for their unique talents, experience, and insights. And we all can do our part by validating each other's experiences and believing each other.

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Ludmila N. Praslova, PhD, SHRM-SCP, uses her extensive experience with neurodiversity and global and cultural inclusion to help create talent-rich workplaces. The author of *The Canary Code,* she is a professor of graduate industrial-organizational psychology and the accreditation liaison officer at Vanguard University of Southern California. Follow Ludmila on LinkedIn.

Survey: How People Experience Chronic Illness at Work

And what their employers are — and aren't — doing to support them.

by Katie Bach and Gretchen Gavett

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Jasu Hu

Tens of millions of people worldwide have long Covid, a multisystem illness that can arise after a bout of Covid-19. It's one of several complex chronic medical conditions with symptoms like fatigue, post-exertional malaise, cognitive impairment, pain, and neurological and sleep issues. (Myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS; postural orthostatic tachycardia syndrome, or POTS; and Ehlers-Danlos syndrome, or EDS, are others, to name a few.) What is it

like to work while experiencing one of these conditions? And how much do people's colleagues and managers know about how to accommodate employees who have them?

Our new Big Idea feature article, "Long Covid at Work: A Manager's Guide," shares a framework for flexible work options that organizations can use to ensure that people with chronic illnesses can contribute and thrive. But we also wanted to hear directly from HBR readers and people from the chronic illness community to get a sense of how their work lives have been impacted — and specifically, whether employers were missing the mark.

So, we invited people to share their perspectives on chronic illness in the workplace via an online survey. More than 200 people responded, almost equally divided between people who identified as having a chronic illness that impacted their day-to-day activities and people who did not (whom we call "non-ill respondents" throughout this article).

After reviewing responses to our questions, a few key findings stood out. (Note that the below represents only the views of the 200-plus respondents, not the broader population.)

Most non-ill people who responded said that their organizations were supportive of chronically ill workers, but those directly affected disagreed.

When asked if their employers were understanding of employees with health issues, 60% of non-ill respondents agreed. Only 36% of people who identified as having chronic illnesses agreed that "my employer is understanding of my illness."

As one chronically ill respondent said, "Long Covid is not yet understood as a chronic illness…My boss was understanding for the first year, but then told me she'd been 'patient' while I 'recovered' and now

it's time for me to get back to work." Another wrote, "Not enough people understand the toll of it, or the extent of it, and it is exhausting to have to fight the disease and educate people at the same time."

"My company has not communicated with me since taking leave. It's like being thrown in the trash when your usefulness is less than their productivity ratio," shared a third respondent. "I have more than 20 years of experience with this firm, but I'm only 45…I'm angry and frustrated and sad."

A fourth put it succinctly: "Most employers aren't gonna believe you."

Part of the problem, according to some, is that long Covid symptoms — and how "ill" someone appears — can vary day-to-day. "Long Covid means that one day I can work at almost full capacity and the next I can barely get out of bed. Because of the unpredictable nature of the illness, it is supremely difficult to manage not only your own but the expectations of managers and co-workers," said one person. "You want that report Friday? Sure thing! [I'll] get off to a great start and then Wednesday through Friday the brain fog hits and you can't remember the last sentence you read and you have a migraine from staring at a screen too much. Your cortisol level shot through the roof because you were excited…to be working on something fun and important again, but now you've got a raised heart rate of over 140 whilst sitting down. By Thursday you slept 11 hours and woke up tired and [felt] like you're getting the flu. You can barely move. You call in sick. You feel like s—. You're not going to finish the report. You let people down, you feel guilty for being sick, [and] people don't understand how you were perfectly fine Monday and Tuesday but now you're not."

Three-quarters of chronically ill people who took the survey are still working, but many had to make significant changes and sacrifices to do so.

We asked people with chronic illnesses how their medical conditions impacted their work. At some point during their illness:

- 30% had to reduce the hours they worked.
- 27% had to take a medical leave of absence.
- 13% had to find a new job.
- 17% had to stop working altogether.

Currently, 75% of respondents say they still work but that they had to cut back on other activities in order to do so. "It really stinks when every break and lunch is spent resting, so all your awake, productive time is spent at work. [There's] no free time to manage the rest of your life," one respondent said. "It's not sustainable long-term unless someone else in your life is…cooking, doing the dishes, taking out the trash, doing the laundry, etc." Another noted, "The little things take so much energy it takes everything out of you, and any personal time is just spent recovering."

A quarter of chronically ill respondents had disability accommodations, but many others reported barriers to access.

Twenty-seven percent of chronically ill respondents said that they had disability accommodations for their medical conditions. The most common were the flexibility to work from home and flexibility around working hours (total hours worked, specific times worked, and the like).

Examples included:

- "Work[ing] from home, accessible training, a special keyboard, extra days to recover from work travel, [closed] captions."
- "WFH during flare, virtual option (hybrid), chair for sitting available, HEPA [high-efficiency particulate air filter] in room."

- "More time to complete projects. Shifting deadlines when appropriate. Time off work when symptoms flare. Work from home is #1."
- "Later start time due to sleep disorders and fatigue."

Some respondents said they didn't need formal accommodations due to the nature of their job (for example, a job that is already remote) or because they had informal agreements with their managers (such as keeping their camera off during meetings).

However, other respondents cited barriers to accessing accommodation. The most common was fear of disclosing health status due to stigma or concern about repercussions. "It's too embarrassing to ask and I think the management team will think less of me if they know how sick I am," said one respondent. Another wrote, "Bringing this up to an employer is risky due to not knowing how they might react to having an employee that might be ill…Most working professionals have a reputation at stake, and to let our employer know about our condition might put us in a bad spot and potentially not have opportunities for professional growth and promotions."

One employee talked about the tension between needing support and wanting to appear "well": "Because long Covid is an invisible disability, I am often stuck between wanting to pass as non-disabled so I am not excluded from various activities, projects, etc., and needing people to understand that I can't function the way I used to. I end up feeling like I need to read as simultaneously sick and well."

These concerns may not be unfounded. Some respondents who had disclosed their condition shared that they had experienced challenges. "Once people get wind of my disabling condition, they begin to infantilize me and really put more focus on what they think my limitations are rather than what I actually state as my limitations," noted one person. And from another: "When my employer learned

about my illness, I was trusted less and given fewer opportunities for development. Nothing about my performance changed other than needing time off to recover."

An additional barrier to accommodation access was the challenge of getting a diagnosis or confirmation of disability. As one person said, "Few doctors know anything about long Covid. Getting one to even acknowledge that you have it is at best months of irrelevant tests to 'rule out' everything else under the sun." A second shared, "My employer didn't recognize long Covid and expected that I was fit to work on my return," while a third wrote, "Employers do not understand the impact of my disability on my day-to-day life, and they are not willing to trust my word either."

Some non-ill people who took the survey also shared their thoughts on the best approaches to accommodation. Many focused on organizational culture and communication.

In addition to highlighting specific accommodation practices (for example, remote or hybrid work and allowing flexibility around hours worked, schedules, and time off) — which generally aligned with the accommodations that chronically ill respondents pointed to — many non-ill respondents spoke about the importance of an organization's culture, approach to inclusivity, and openness of communication.

"I think companies should create environments where employees feel safe enough to be honest about their capacity and where they might need help," said one person. Another stressed that "a cookie-cutter approach or policy may not achieve the objective of accommodating health condition and results. Compassion and a shared interest in achieving results should be the way."

"I think the most important is culture: manager [sensitivity] and psychological safety," reported a different respondent. "People with

chronic illnesses may just need ecosystems that are supportive, where they feel safe and heard by managers and peers and that they will not be reprimanded for calling out their needs, which may be different for each individual."

Other non-ill respondents spoke about the need to think more inclusively about how to deliver against organizational priorities.
"There should be space for individuals to choose how they do their work and deliver results," said one person. "If the role allows, performance should not be linked to aspects like hours worked, breaks taken, and check-in and checkout timing and rather to actual deliverables." Another noted the importance of job tailoring as an option, "by first listening to and understanding the needs of the employee's illness and then co-creating a plan with the employee and a third-party expert in the particular condition. From the organization's perspective, the goal should be what can that person deliver particularly well, how much of it, and in what way and then putting in place a system that can support and supplement this delivery for required results."

Several chronically ill respondents left us with a final thought: They can still achieve as much at work as they did before they became ill — just not in the same way they did before.

"[It's] possible to achieve the same results even with my health limitations," noted one person. "However, the way I work and number of hours I work must change to within my energy capacity (e.g., working from home instead of the office, flexible time of day, fewer meetings, time for rest periods at home during day, etc.)." Another emphasized the importance of pacing, or "the ability to move forward when I'm doing all right and scale back activity or stop when I'm feeling worse. This allows me to maintain my productivity long-term, and many of my healthy friends say I get more done in the average day than they do. This requires employers to be understanding of my health limitations and

not make workplace attendance into a lever of control, but make semi-flexible deadlines to reach particular goals and objectives or finalize products instead."

A third person perhaps said it best: "I just work differently now."

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Katie Bach works with companies to improve job quality and employee experience. She has written extensively about the labor market impact of long Covid, including as a former nonresident senior fellow at the Brookings Institution, and serves as board chair of PolyBio Research Foundation, which focuses on complex chronic conditions. Follow her on LinkedIn.

𝕏 @kathrynsbach

Gretchen Gavett is a senior editor at Harvard Business Review.