

Speaker Series Summary Episode 10: Workplace Accommodations

Overview

In this Speaker Series episode, we talked with Ms. Michele Dearing, a member of our board of directors and attorney in Washington, DC. Michelle is a GBS survivor and currently lives with CIDP. She's very active in many of our patient programs and advocacy initiatives.

Summary

<p>Disclaimer</p>	<p>The information provided in this webinar comes from Michelle's personal experience and is not legal advice.</p>
<p>Michele's Story</p>	<p>So, it was definitely a rollercoaster. It was a journey with ups and downs. I'm not only a GBS survivor, but I'm also currently a CIDP patient. So, when I addressed my employer about accommodations, it was during a time in which, you know, I was newly diagnosed with CIDP, perhaps maybe like a year out. I was definitely having a lot of flare-ups. My neurologist had placed me on an infusion regimen. So, I was getting IVIg at home for several hours. There came a time when I started to travel a lot for work because I did not have an office job.</p> <p>So, I was having some difficulty with fatigue and doing a lot of typing. Particularly in the morning, it seemed like my symptoms would be a little heightened during those periods of time. I was just trying to figure out the best way to be able to meet not only my neurologist but also to get my infusions. At that time, my treatment regimen consisted of a five-day initial loading dose. Thereafter, I would get infusions, usually about every three weeks, and one infusion would last anywhere from six hours to eight hours. For those patients who've had to get IVIg treatments, you know, sometimes it lasts a little bit longer. You may have some reactions and things.</p> <p>So, I certainly, needed that flexibility. At the time that I approached my employer about what I needed for accommodations, I was traveling a lot. They were not aware of my medical condition at the time. So, the first thing that I did was try to arm myself with information; how do I have this discussion? What do I exactly disclose to them?</p>

Michele's Story

Obviously, with this being a rare disease, I went to the foundation's webpage and utilized that description to talk to my employer about what this condition is. It wasn't an easy process. I was in fact the first employee who had requested any accommodation. So, they were really looking to me to provide some suggestions on what type of accommodation I needed. In addition, I had to take an active role in having these conversations with my neurologist because there were quite a few forms that I needed to fill out.

So, it was difficult to make sure that I was providing the appropriate information without necessarily oversharing to the extent that I didn't have to. So ultimately, some of my accommodations resulted in a period where I had a reduced work schedule. As a result, it created a reduced schedule with retrospectively, reduced pay. So as a single individual, that was quite a big deal for me. I knew that I needed to try to keep this job so that I had the appropriate healthcare to get the actual care that I needed.

Did your employer require you to have a doctor's note, or did they need you to provide some sort of proof of your condition?

Accommodations are something that you can ask for based upon a federal law called the **Americans with Disabilities Act. The ADA states that if you have a qualified medical impairment, any condition that limits your ability to perform certain functions of your job, you need to provide at least some level of information to your employer.**

I did disclose my diagnosis. Though not required, you must provide enough information for your employer to understand your limitations and how often you experience them. So, I worked with my neurologist to draft a letter that explained how I've been his patient since 2010, and I was required to have an infusion regimen. He went into some of the residuals that I have, such as excessive fatigue, numbness, and tingling in my hands and feet. That allowed my employer to kind of understand perhaps some ways that we might be able to make accommodations. So, I was able to request telework as an accommodation that gave me an opportunity to take breaks and rest.

What is FMLA?

I needed flexibility for my infusion start and end times, so that was something I negotiated. Then you have the ability to take what's called intermittent leave. Intermittent leave is something that an employee can seek under what's called the Family Medical Leave Act (FMLA), which is also a federal law. FMLA is a provision regulated by the Department of Labor giving you federal protection.

Requirements for FMLA

- FMLA leave is only for employers with 50 employees or more.
- The employee must have worked for that employer for at least 12 months and at least 24 hours per week.

I utilized that leave to get my infusions, if I had neurological symptoms at home for which I just wanted an hour or two of leave while I'm working, or to go to various doctor's appointments.

If your employer is not required to follow this act because they don't have the number of employees at play or you haven't been at your employer for long enough to qualify, you can still certainly get and request unpaid leave as accommodation.

Should patients disclose their condition during the interview? Is there any legality around withholding their medical information?

It's certainly a personal decision. I would encourage patients to consider looking at some online resources that are available to educate themselves about what their rights are, what their obligations are, and what they need to disclose.

Under the ADA, you're not legally required to disclose that you have any type of disability. In fact, in the interviewing phase, an employer is not permitted to ask you any disability-related questions.

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What comes to play is at that job offer. At the job offer, an employer can ask you disability-related questions. So, think of perhaps a police officer or certain jobs that have a physical fitness test. They're able to get into whether you can physically perform the job with or without accommodation.

**What is considered reasonable accommodation?
What would be considered reasonable accommodation specifically for CIDP?**

A reasonable accommodation should not subject the employer to undue burden. Your employer is not required to provide the accommodation that you request, but they are required to provide accommodation that gets to the heart of your limitations.

Example: With respect to my numbness and tingling, which sometimes would impact my ability to type, I requested and did receive a program called Dragon Software, a voice-to-text software. It wasn't terribly expensive, and it wasn't something that created a hardship on my employer.

I also had accommodations where **non-essential functions of my job were relieved** for me. So, for example, I did volunteer work with a part of my job, you know, kind of like took on some extra work because that really wasn't part of my official job. They reassigned that to someone else.

Some examples of accommodations can be

- Reassigning an employee to a new job that's available can be an accommodation.
- Telework/remote work
- Breaks throughout the day
- Making the workplace more accessible

How do you determine what your needed accommodations are?

First, understand the areas in which you lack the ability to function at a normal level. Then, explain to your employer that you need certain accommodations based on the areas where you become more disabled.

Visit the [Job Accommodation Network](#). It's a free website that will provide consultations to employees and employers to try to identify types of accommodations that may work for a particular circumstance. They have a free employee guide. There's also a function there that you can add your limitation. Let's say you have a hearing impairment, or you have fatigue. They will give you potential accommodations that could address that.

<p>What is considered an unreasonable accommodation? Would requesting a ramp be considered unreasonable?</p>	<p>Accommodations that take away from the essential function of your job are considered unreasonable. Installing a ramp may be unduly burdensome and would add costs to the company. Consult your employer because if you work in a public space the ADA requires these spaces to have accessible entrances.</p>
<p>How can I be certain that I won't lose my job? Is there any way to guarantee that my employer is not going to let me go once I've disclosed my condition and asked for accommodation?</p>	<p>There is no guarantee that you won't lose your job. However, as I mentioned before, there are laws at the federal level, such as the American with Disabilities Act (ADA), which prohibits discrimination based upon disability, whether it's an actual disability or perceived disability. This includes protection against termination, hiring, job duties, reassignment, or a change of fringe benefits on the basis of your condition.</p> <p>If you've disclosed your disability to your employer in efforts to seek accommodation, then I would encourage you to visit an attorney, perhaps one that specializes in labor and employment matters or a disability lawyer.</p> <p>The Equal Employment Opportunity Commission (EEOC) is a federal agency that is tasked with ensuring that those who fall under the protection of these federal laws are not discriminated against.</p>
<p>What's the first thing that you should do if you feel like you're being discriminated against?</p>	<ol style="list-style-type: none">1. Contact and look at some of those free resources.2. Consider a free consultation with a disability or employee law attorney to kind of get a sense of what your rights are.

<p>Is there free legal advice? Are there any websites that offer free legal advice?</p>	<ul style="list-style-type: none">• For potential legal advice, a lot of states do have a legal aid service. A lot of times these services can be income-based. In addition, all states have what's called their state bar. The state bar may offer free resources and free legal consultations. They may have a directory of attorneys that can provide either pro bono, which means free, or reduced rates when providing legal advice.• Social workers are a good resource but will not provide legal advice.• The Department of Labor is a federal agency that oversees FMLA, and they have free resources.
<p>Have you ever been asked to have one of your physicians or healthcare providers contact your employer other than just writing something up?</p>	<p>It's not common.</p> <p>For me personally, that was not my experience. In my experience, a letter from my neurologist was sufficient for both my accommodations. For my FMLA leave, there are required forms your physician must provide.</p> <p>I think the best course is to first talk to your provider rather than giving your employer full access because there are HIPAA and privacy issues that could be at play. When you are seeking leave under FMLA or an accommodation, there's no requirement that you disclose all your medical conditions.</p>
<p>Do some people work through their infusions?</p>	<p>Yes, it was a part of my accommodation request. I explained that I'll be able to do some work—maybe not, you know, all of it. Yet, I can certainly do some work, check emails, and things of that nature while I was infusing at home.</p> <p>You may try an accommodation, but it ultimately doesn't work. So, it's going to be an ongoing conversation with your employer.</p>

<p>Are there any accommodations in the workplace that would be available for caregivers?</p>	<p>A care partner could seek medical leave. In particular, they could seek medical leave under the Family Medical Leave Act. The Family Medical Leave Act allows someone to seek protected leave not only for themselves but also for the care of a family member. I encourage patients to go and look at the Department of Labor's website because I'm pretty sure it's going to be limited.</p> <p>There is a specific scope of who qualifies as a family member, but certainly, your spouse and child are going to certainly qualify for that. It's the same kind of process as someone seeking leave for their own care. There's a required form that the care partner would have to complete, and the patient's provider will need to fill it out. Most importantly, note that the patient's medical condition, such as how long they're going to be out, will be shared between all parties.</p>
<p>Can I take some time off using sick leave or vacation leave?</p>	<p>FMLA protects you from an employer terminating you while you're on leave. Furthermore, the employer cannot take away your benefits while you're on leave.</p>
<p>Are there a certain number of weeks that FMLA offers?</p>	<p>Yes, so FMLA qualifies for 12 weeks of unpaid leave. The beauty of FMLA is you don't have to take the 12 weeks in a big chunk. You can take intermittent leave.</p> <p>For example, let's take a hypothetical patient who has infusions every three weeks. So, they leave just for those three days. Let's say your infusions, just for the sake of this conversation, are only three hours. You could take three hours of leave for three days and work the rest of the time.</p> <p>Consult your employer to see if your leave rolls over next year. FMLA leave may be determined by your state and employer.</p>
<p>Are there any other resources available for care partners like that that don't quite fill the requirement of FMLA, such as siblings?</p>	<p>It could be if you have guardianship. If a sibling has guardianship, that might qualify. It doesn't have to be a biological child. It can be adopted children as well. So there has to be some level of tie. So, I'm not sure about the sibling, but I would certainly encourage, if it's a sibling situation, to seek legal advice because, you know, oftentimes the legal world can change.</p>

<p>Any other benefits or resources out there?</p>	<p>I would encourage patients to investigate whether their employer has short-term disability or long-term disability. Short-term disability could provide at least a percentage of your pay while you're out. It's all going to depend on the insurance that your employer has negotiated. It's usually going to be at least some kind of seven-day period, which would be great for people who are newly diagnosed and need to be in the hospital for a period of time.</p> <p>Some employers have a program that's called EAP, or Employment Assistance Program. EAPs may have a host of resources and can be free of charge. If your employer has an EAP, they're usually confidential. It's voluntary. You may want to ask your HR department if that's available or if your job has a website that lists the benefits available to its employees.</p> <p>Example: I did participate and utilize the EAP services. In fact, I worked with a therapist that helped me navigate the emotions that were associated with the stress associated with negotiating those accommodations with my employer.</p>
<p>Was there any specific place on our website, conversations, or events that you recommend other people connect with at the Foundation here?</p>	<p>First and foremost, the descriptions of the conditions helped ease the burden of explaining my condition to my employer. If they needed more information, I would direct them to the website.</p>
<p>Closing Remarks</p>	<p>Advocate for yourself and be equipped with as much information as you can so that you can really have informed conversations with your employers and make informed decisions about what would work best for you.</p>

Relevant Resources

[Job Accommodation Network](#)

[Advocacy Resource - Fact Sheet About the ADA](#)

[Educational Videos About GBS, CIDP, and MMN](#)

[U.S Department of Labor Website](#)