



Discrimination and Patient Rights

Living with chronic illness has many inherent challenges. When discrimination occurs, it not only adds insult to injury, in some cases, it can put patients' lives at risk.

By Trudie Mitschang

ANYONE DIAGNOSED with an invisible chronic illness has likely had to confront the perception that they don't look sick. When the sentiment is expressed by family or friends, it is undoubtedly frustrating. But, when doubt about diagnosis creeps into conversations about job performance, access to care or the need for special accommodations or medical leave, the repercussions can have far more serious consequences for both chronically ill patients and their families.

According to the Chronic Disease Coalition, patient discrimination comes in many forms. At its root, discrimination is about treating someone differently because they have a particular trait. For patients, discrimination means being treated differently because of their disease or disorder. One of the most dangerous forms of discrimination against patients is often doled out by health insurance carriers. The Coalition reports cases in which insurers have attempted to force

kidney patients off their plans; documented fibromyalgia and cancer patients who have had their financial assistance payments rejected; and denied care to patients with health issues such as functional neurological disorders because the insurance company did not believe their disease existed.¹

Obviously, being denied access to care is the most extreme form of patient discrimination, but more subtle forms of bias can also impact patients' quality of life. For example, chronic disease patients may find themselves excluded from participating in certain professions and occupational activities because of their condition. One such example existed until recently: Patients with diabetes were prohibited from obtaining a commercial trucking license. In other instances, employers' lack of sick leave protection can require chronic illness patients to make an impossible choice between the financial security of a job and their basic health needs.¹

Patient Rights Under the ADA

The Americans with Disabilities Act (ADA) was enacted by the U.S. Congress in 1990. Akin to the Civil Rights Act of 1964, the ADA is designed to protect individuals from any form of discrimination based on disability. In addition, it requires covered employers to provide “reasonable accommodations” that allow employees with disabilities to perform their jobs effectively, and it imposes accessibility requirements to address the needs of those with physical limitations.²

In 2008, the original language within certain sections of the ADA was amended to address the need for a broader interpretation of the term “disability.” The changes were needed because in its previous draft, the courts had defined what constitutes a disability so narrowly that hardly anyone could qualify. The amended language now states a disability is “any physical or mental condition that substantially limits a major life activity.”² Under the law, what constitutes a major life activity includes basic functions such as walking, reading, bending and speaking, as well as an array of bodily functions, including the immune system, cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions.

As members of Congress explained, “The ADA Amendments Act rejects the high burden required [by the Supreme Court] and reiterates that Congress intends that the scope of the Americans with Disabilities Act be broad and inclusive. It is the intent of the legislation to establish a degree of functional limitation required for an impairment to constitute a disability that is consistent with what Congress originally intended.”³

In a nutshell, the ADA Amendments Act makes it easier for individuals seeking protection to establish they actually have a disability. The amended guidelines cover the following individuals:

- Employees with a physical or mental impairment that substantially limits a major life activity
- Employees with a history of impairment (One cannot be discriminated against based on a previous disability.)
- Employees whom the employer regards as disabled (This protection is applicable if the employer discriminates against an employee based on its incorrect belief that the employee has a disability.)

What Patient-Centered Discrimination Looks Like

The Patient Protection and Affordable Care Act (PPACA) was passed by the 111th Congress and signed into law by President Obama in March 2010. Often referred to as the

ACA, it was designed in part to prevent health insurers from discriminating against patients with chronic or pre-existing conditions. Yet, despite progress, there are many types of discrimination the chronically ill continue to face.¹

Step therapy or “fail first”: Patients are forced to try and fail cheaper treatments before being allowed to obtain the treatment prescribed by their doctors. Here is what this looks like: A doctor prescribes a specific treatment to ease a patient’s health condition symptoms, but the insurer refuses to cover the drug and instead requires the patient to try a different, cheaper option. If the cheaper option fails to ease symptoms, only then can the patient obtain the treatment originally prescribed.

Premium assistance bans: Insurance companies target patients with chronic diseases by rejecting their premium payments if they rely on financial aid from nonprofit organizations.

Co-pay assistance bans: Insurers reject coverage to patients who rely on financial aid from hospitals, nonprofits such as CancerCare or other organizations to cover their co-pays.

Nonmedical switching: Insurance companies limit prescription drug coverage to less-expensive medications, requiring patients to use a different one than prescribed or forcing them off current, effective treatments.

Effective self-advocacy begins with knowing one’s rights and understanding the laws that help define those rights.

Workplace discrimination: People with chronic conditions frequently must worry not only about their health but about their jobs since employers’ policies may be murky or unfair when it comes to sick leave or other time off. They might be made to take unreasonable tests because of their disease, or face barriers to taking their needed medications.

School-based discrimination: Students with chronic diseases may face discrimination in the types of activities they are allowed to participate in, or how and whether they’re able to access their prescribed medical treatments.

PI-Specific Concerns in the Workplace

Primary immunodeficiency diseases (PIs) and other invisible chronic conditions present a unique challenge for both employees and employers. These challenges are highlighted by statistics from a study conducted by researchers at Cornell University's Employment and Disability Institute, which found that of the employment disability discrimination charges filed with the Equal Employment Opportunity Commission (EEOC) between 2005 and 2010, the most commonly cited conditions were invisible ones.⁴

Despite laws in place to protect them, many individuals with invisible illnesses such as PI choose not to disclose the illness, either during the hiring process or after diagnosis. Some fear being viewed with pity or being judged "incapable," while others assume it will affect their chances of being hired or promoted. But, experts say one of the main reasons it may be a wise decision to disclose any disability is for employees to put themselves in a position to request a reasonable accommodation. Obviously, if employees feel they can perform the essential functions of the job without accommodations, they may not want to disclose the nature of their illness.

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Here are some factors patients might consider:

- Under the ADA, employees must disclose they have a disability in order to be protected.
- Employees need to disclose only those medical conditions that require an accommodation.
- Employees do not need to disclose their disability to coworkers.
- Employees should be prepared to discuss with their employer what reasonable accommodations they need, including a modified work schedule, assistive devices and technology, or the need to sit rather than stand to perform a job.

Employees can disclose their chronic illness at any time during the hiring process. If they decide to disclose during the interview process, they should be prepared to provide examples of how they have performed job duties in the past, especially tasks related to the job for which they are applying. If they decide to wait until an offer has been extended, the ADA states the employer "cannot withdraw the job offer solely because you revealed you have a disability. Instead, the employer can withdraw the job offer only if it can show that you are unable to perform the essential functions of the job (with or without reasonable accommodation), or that you pose a significant risk of causing substantial harm to yourself or others."⁵

You Suspect Discrimination: Now What?

When individuals suspect an employer has denied them a job or an equal opportunity to apply for a job due to a visible or invisible disability, has refused a request for reasonable accommodation or has made illegal medical inquiries or required an illegal medical examination, they should contact the EEOC. Employees are required to file a complaint of discrimination within 180 days of the alleged offense. They may have up to 300 days to file a charge if a state or local law provides relief for discrimination on the basis of disability, but to protect their rights, it is best to contact the EEOC as soon as possible to discuss all options.

According to the EEOC, if it is determined an employee has been discriminated against, that employee is entitled to a remedy that will place him or her in the position he or she would have been in if the discrimination had never occurred. This means the employee may be entitled to hiring, back pay or reasonable accommodation. The employee may also be entitled to reimbursement for attorney's fees.⁶

Understanding the Family Medical Leave Act

If individuals have a chronic illness and are still able to work, there's a good chance that between the illness and the number of medical appointments required, they will quickly use up any accrued sick or paid time off. Once time off is used, patients might be able to invoke the Family Medical Leave Act (FMLA).

FMLA applies to all public agencies, including state, local and federal employers, local education agencies (schools) and private-sector employers who employed 50 or more employees in 20 or more workweeks in the current

or preceding calendar year, including joint employers and successors of covered employers. Small businesses with a handful of employees are not required to provide FMLA benefits.

To be eligible for FMLA benefits, an employee must:

- Work for a covered employer;
- Have worked for the employer for a total of 12 months;
- Have worked at least 1,250 hours over the previous 12 months; and
- Work at a location in the United States or in any territory or possession of the United States where at least 50 employees are employed by the employer within 75 miles.

A covered employer must grant an eligible employee up to a total of 12 workweeks of unpaid leave during any 12-month period for one or more of the following reasons:

- For the birth and care of a newborn child of the employee;
- For placement with the employee of a son or daughter for adoption or foster care; and/or
- To care for a spouse, son, daughter or parent with a serious health condition.

An employer is required to maintain the employee's group health insurance during FMLA. In addition, the employee is required to make whatever contribution to that insurance that he or she was making prior to taking leave. When the employee returns to work, he or she has rights to job restoration. Upon return from FMLA leave, an employee must be restored to the employee's original job, or to an equivalent job with equivalent pay, benefits and other terms and conditions of employment.

Becoming One's Own Advocate

Self-advocacy is a concept that has gained momentum in recent years. Becoming empowered to speak up for oneself, make one's own decisions about life and treatment plans, learn how to get information and understand it, and know one's rights and responsibilities can seem daunting at first.

Following are steps toward self-advocacy:

1) *Understand how health insurance works.* Many Americans don't understand the basics of their coverage, and understandably so since health insurance is complicated. A recent survey from the Kaiser Family Foundation found more than four in 10 respondents don't understand basic health insurance terms, and even fewer could calculate how much a patient would owe under certain hospitalization circumstances. Knowing how insurance works helps patients

navigate the healthcare system with less chance of ending up with costly, unexpected medical bills.

2) *Review medical bills for errors.* An estimated eight in 10 medical bills contain errors that go undetected without the sharp eye of an empowered patient. Medical bills can be difficult to decipher. Patients should be sure to ask questions as they arise, even if they seem "obvious or ridiculous."

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Knowing One's Rights

Effective self-advocacy begins with knowing one's rights and understanding the laws that help define those rights. Patients are encouraged to familiarize themselves with the ADA and the specific laws that relate to their condition. Information about the ADA can be found at www.ada.gov.

The truth is, whether engaging in discussions with policy-makers, choosing to have a medical procedure, applying for a job or negotiating a special accommodation in the workplace, self-advocacy can dramatically enhance self-confidence and minimize chances patients will be subjected to unfair discrimination. ■

TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.

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