



Working with Chronic Illness: Patients' Rights

The Americans with Disabilities Act and other laws provide protections for patients with chronic illness.

By Trudie Mitschang

FOR THOSE LIVING with an invisible chronic illness, the common accusation “You don’t look sick!” can be both frustrating and insulting. But, when that judgment finds its way into discussions regarding job performance, the need for special accommodations or medical leave, the repercussions can have far more serious consequences for both chronically ill patients and their families.

The Americans with Disabilities Act (ADA) was enacted by the U.S. Congress in 1990. Similar 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.¹

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 that a disability is “any physical or mental condition that substantially limits a major life activity.”¹ 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.²

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 layman’s terms, the ADA Amendments Act makes it easier for individuals seeking protection to establish that they actually have a disability. The amended guidelines⁴ 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.)

ADA Coverage: What Is a Qualified Worker?

Title 1 of the ADA states that employers with more than 15 employees must provide reasonable accommodations to individuals with disabilities.⁵ While that language sounds somewhat inclusive, there are a lot of specific qualifications that could be left open to interpretation. For example, the ADA states that only “qualified workers” with disabilities are protected.¹ Under the guidelines, a qualified worker with a disability is someone capable of performing the essential duties of the job in question, with or without a reasonable accommodation by the employer. For example, typical duties of a call center’s customer service representative would include answering phones, drafting correspondence and addressing complaints. An individual applying for that job would be expected to perform those tasks, and if needed or requested, an employer must provide a reasonable accommodation — an adjustment or modification that allows the employee to do the job.

According to the Reasonable Accommodation and Undue Hardship section of the ADA,⁶ any time an employee indicates that he/she is having a problem and the problem is related to a medical condition, the employer should consider it a potential request for accommodation.

Examples of reasonable accommodations under the guidelines include:

- An employee is having trouble getting to work on time because of medical treatments and needs an approved later start time.
- An employee needs six weeks off to get treatment for a back problem.
- A new employee who uses a wheelchair informs the employer that her wheelchair cannot fit under her desk in the office.

An example of a request that does not meet the guidelines is:

- An employee tells his supervisor that he would like a new chair because his present one is uncomfortable.

Although this is a request for a workstation change, it does not meet guidelines unless the discomfort is associated with a medical condition.

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Understanding Undue Hardship

The ADA also protects employers, a fact many employees tend to overlook. The guidelines state that an employer is not required to provide a reasonable accommodation if doing so would create an “undue hardship.”⁶ An undue hardship is defined as something that presents significant difficulty or expense for the business. These factors determine whether an accommodation creates an undue hardship:

- the nature and cost of the accommodation
- the financial resources of the employer (larger companies can usually afford to do more than smaller ones)
- the nature of the business, including size, composition and structure
- accommodation costs already incurred in the workplace

If the cost of an accommodation threatens the financial viability of the organization, regardless of the reason, it’s probably an undue hardship and not required. However, according to the Equal Employment Opportunity Commission (EEOC), the

FAQs for Primary Immunodeficiency Patients

Q. How do I apply for disability?

A. When filing a claim, compile the most current records from your medical team such as your immunologist, rheumatologist, etc., and submit them at the time of the application. A letter from a physician documenting your inability to maintain full-time employment, and any supporting evidence such as lab findings, MRIs, X-rays is also helpful. It's a good idea to be proactive and contact the disability examiner assigned to your case every few weeks to make sure they have all the requested information they need to process your claim. When asked to fill out a Disability Determination Services form, be as detailed as possible regarding your job duties, rate of pay, supervisory duties and physical limitations. Some individuals are also asked to submit to a medical exam. For more detailed information, visit www.ssa.gov.¹⁰

Q. What is a good resource for information about the American Disabilities Act (ADA) and Family Medical Leave Act (FMLA)?

A. The Immune Deficiency Foundation recommends the Patient Advocate Foundation. The site has a resource titled First My Illness, Now Job Discrimination: Steps to Resolution. Within that resource is a section called Understanding the ABCs of the ADA and the FMLA that explains in detail what you need to know about these two laws. More information can be found at www.patientadvocate.org.

Q. Does the FMLA apply to infusions for an employee or an employee's child?

A. The FMLA¹¹ allows for leave to receive "continuing treatment by a healthcare provider," which can include recurring absences for infusions. According to the law, employers with 50 or more employees must provide up to 12 weeks of unpaid, job-protected leave to employees who have worked for the employer for at least one year.

An employee's children, spouse and parents are immediate family members for purposes of the FMLA. The term "children" does not include dependents over the age of 18 unless they are "incapable of self-care" due to a mental or physical disability that limits one or more of the major life activities defined by the ADA. To learn more, go to www.dol.gov.

majority of accommodations cost less than \$500.⁶ For most employers, that makes them reasonable and easy to implement.

To Tell or Not to Tell: Addressing the Issue of Invisibility

Primary immunodeficiency (PI) and other invisible chronic conditions present a unique challenge for both employees and employers. The challenges are highlighted by statistics from a study conducted by researchers at Cornell University's Employment and Disability Institute. The study found that of the employment disability discrimination charges that were filed with the EEOC between 2005 and 2010, the most commonly cited conditions were invisible ones.⁷

Despite the 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. Some factors to 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.

Keep in mind that 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've performed job duties in the past, especially tasks related to the job for which they are interviewing. If they wait until an offer has been extended, the ADA states that 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."⁸

Taking Leave When Needed

What happens if a chronic illness is diagnosed during tenure on an existing job? Employees may be entitled to medical and/or disability-related leave under both the ADA and the Family and Medical Leave Act (FMLA). In addition, state workers' compensation laws have provisions that may apply.⁹

Workers' compensation is a form of insurance that provides financial assistance, medical care and other benefits for employees who are injured or disabled on the job. Except for federal government employees and certain other groups of employees, workers' compensation laws are administered at the state level. Because each state has its own system, coverage varies. As a general rule, workers' compensation laws apply to all employers with one or more employees. In most states, all employees are covered. An on-the-job injury triggers coverage.

Under medical and disability-related leave rules, injured employees receive varying amounts of paid leave, depending on the state and the nature of the injury. If employees need time off because of a medical or disability-related issue, they may have rights under several laws at the same time. In certain circumstances, provisions of the ADA, the FMLA and workers' compensation laws can apply.⁹ For example, a workers' compensation injury that requires hospitalization or incapacitates an employee for more than three days and requires continuing treatment by a healthcare provider generally qualifies as a serious health condition under the FMLA. If the injury causes a permanent mental or physical impairment that substantially limits a major life activity, that same employee could be entitled to additional leave as a reasonable accommodation under the ADA.

In addition, several states have enacted their own family and medical leave laws, some of which provide greater amounts of leave and benefits than those provided by the FMLA. State laws may also apply to employees who are not eligible for benefits under the FMLA. In general, when employees are covered by both federal and state family and medical leave laws, they are entitled to the greater benefit provided under the different parts of each law.

Filing a Charge of Discrimination

If employees think an employer has denied them a job or an equal opportunity to apply for a job based on a visible or invisible disability; has refused their request for reasonable accommodation; or has made illegal medical inquiries or required them to take an illegal medical examination, employees should contact the EEOC. Timing is important, because employees

are required to file a complaint of discrimination within 180 days of the alleged offense. Employees 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.

UNDER MEDICAL AND DISABILITY-RELATED LEAVE RULES, INJURED EMPLOYEES RECEIVE VARYING AMOUNTS OF PAID LEAVE, DEPENDING ON THE STATE AND THE NATURE OF THE INJURY.

According to the EEOC, if it is determined that 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. ■

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