



As someone living with a chronic and potentially disabling condition, it's important to know that there are laws in place to protect you and guarantee certain rights in the workplace. Familiarizing yourself with your rights as you choose or navigate your career can help you succeed.

## KNOWING THE LAWS

**The Americans with Disabilities Act (ADA)** is a law that prohibits discrimination solely on the basis of disability in employment, public services, and accommodations.<sup>1</sup> This law also protects employees from retaliation when they invoke their rights under the ADA.

In order to be protected by the ADA, you must have a disability *and* be qualified to perform the functions or duties of a job, with or without reasonable accommodation.<sup>2</sup> In other words, you need to satisfy the employer's requirements regarding things like education, work experience, and skills. Here are some important things to know:

- The ADA defines a disability as a physical or mental impairment that substantially limits a major life activity, such as hearing, seeing, speaking, walking, breathing, or performing manual tasks.
- The ADA was updated in 2008 to make important changes to the definition of the term "disability." A disability is still defined as an impairment that substantially limits one or more life activities, but the list of life activities now includes reading, bending, major bodily functions, and more.<sup>3</sup>
- The 2008 amendment makes it easier to establish that you have a covered disability.
- You are also protected by the ADA if you have a history of a disability.

If XLH makes it difficult to perform some tasks at work, you may benefit from **requesting accommodations** to do your job successfully. Remember, your employer has to provide reasonable accommodation, but employers are only required to provide this for disabilities **of which they are aware**.<sup>2</sup> This means it is your responsibility to tell your employer if you need an accommodation.

## FACING CHALLENGES



Unfortunately, not all employers are knowledgeable, experienced, or fully compliant with all laws, which can make it difficult for employees with disabilities to get the accommodations they need. In more resistant workplaces, you may need to attend a legal proceeding (a hearing) with your employer and show documentation of your condition and need. It's important that you play an active role in advocating for yourself and helping your employer understand your rights and protections under the law.

**Don't give up.**

## TALKING TO EMPLOYERS

It's hard to know when – and if – to tell an employer about your XLH. **You don't need to disclose your condition to your employer.** But choosing to may provide some benefits. The conversation will be more successful if you come prepared.

Think about what you want to say and how to say it. You may want to develop an “elevator pitch” — a simple description that people can quickly understand — so that you have a clear, concise way to explain your XLH.

*Find an example in the Dating and Relationships section of the toolkit.*

Before talking to your employer, write down any accommodations you might need. **Be as specific as possible.** Think about the following questions:

- Do you need to sit down at regular intervals?
- Do you need to stand at regular intervals, or, how long can you sit (for instance, for a long meeting or training)?
- Is there a maximum amount of weight you can lift?
- Would adaptive equipment, such as a lifting aid, hearing assistive technology, adjustable/ergonomic seating, or a footrest, be helpful?
- Do you need a step stool in the community kitchen?
- Do you need hearing caption phones?
- Are meeting rooms located within a comfortable walking distance?
- Do you need an alternate schedule to be able to receive treatments?
- Would you benefit from a closer parking spot?

It might help to talk to an expert. Consider contacting the Job Accommodation Network online at [askjan.org](http://askjan.org) or by phone at 800.526.7234.

Remember that **it's okay to ask** – not only is it your right, but most employers have provisions in their budget to cover the cost to make accommodations.



Jennifer, living with XLH

## UNDERSTANDING HEALTH INSURANCE



Getting your own health insurance as a young adult with XLH may seem overwhelming, but it's not impossible – provided you do a little research to understand your options. Many employers offer health insurance, and for those who don't, you have other options, including:

- **Marketplace Plans:** for people who can't get insurance from their employers or don't qualify for Medicare/Medicaid.
- **Medicare:** a government (federal) health insurance program for people age 65 or older and people under age 65 with certain disabilities and serious health conditions.
- **Medicaid:** a government (federal and state) health insurance program for people with a low income.

**Once you turn 26**, you may no longer be eligible for insurance coverage under your parents' plan(s).

If you're insured through a parent's **employer plan**, coverage will usually end right when you turn 26. If you're insured through a parent's **Marketplace** plan, coverage will last until December 31 of the year in which you turn 26.

In either case, be sure to plan ahead to avoid a lapse in coverage.

See [Understanding Health Insurance](#) for more information on these types of insurance.

If you are buying insurance as an individual in the marketplace or through an employer, always read the **"Summary of Benefits and Coverage (SBC)"** document. The SBC offers an easy-to-read explanation of the health plan's benefits and coverage in simple language.

During the hiring process (and once you've received a job offer), make sure to ask your prospective employer about the health insurance, dental insurance, prescription drug coverage, and any other benefits they may offer. Everyone should be aware of what's covered by their health insurance, but it's especially important for people with disabilities or complex health conditions, since you may have more specific healthcare needs.

## INSURANCE FOR DIFFICULT HEALTH SITUATIONS

**Disability insurance** provides income in the event you're unable to work due to a disability. Short-term disability insurance policies provide a portion of your salary if you're unable to work for 3-to-6 months; long-term disability insurance applies after 6 or more months. However, both short- and long-term policies require you to be disabled for a certain length of time before you can qualify for the benefits. There are many types of plans with different rules, so it's best to do your homework and/or ask your human resources department.

**The Family Medical Leave Act (FMLA)** allows an employee to take up to 12 weeks off per year for medical emergencies, but this is unpaid time. The benefit is that your job is held and you keep the same insurance plan, and at the same cost. This law only applies to companies and employees that meet certain criteria.<sup>4</sup> For more information, read the U.S. Department of Labor's fact sheet on FMLA at: [dol.gov/whd/regs/compliance/whdfs28.pdf](https://www.dol.gov/whd/regs/compliance/whdfs28.pdf). A few states also have Paid Family Leave policies for varying amounts of time. Research your state so you know what's available to you.

## RESOURCES

### Accessible Parking and the Workplace

[adata.org/publication/review-issues-relating-accessible-parking-and-workplace-under-americans-disabilities-act](https://adata.org/publication/review-issues-relating-accessible-parking-and-workplace-under-americans-disabilities-act)

### ADA National Network

[adata.org](https://adata.org)

### Administration for Community Living

[ACL.gov](https://acl.gov)

### “Gaining Independence” Toolkit

[globalgenes.org/wp-content/uploads/2014/07/GG\\_toolkit\\_nine\\_20140725\\_web.pdf](https://globalgenes.org/wp-content/uploads/2014/07/GG_toolkit_nine_20140725_web.pdf)

### Global Genes

[globalgenes.org](https://globalgenes.org)

### Job Accommodation Network

[askjan.org](https://askjan.org)

### National Disability Navigator Resource Collaborative

[nationaldisabilitynavigator.org](https://nationaldisabilitynavigator.org)



## REFERENCES

1. What kind of law is the ADA? ADA National Network; 2019. <https://adata.org/faq/what-kind-law-ada>. Updated September 2019. Accessed September 26, 2019.
2. The ADA: Your Employment Rights as an Individual with a Disability. U.S. Equal Employment Opportunity Commission; 2019. <https://www.eeoc.gov/facts/ada18.html>. Accessed September 26, 2019.
3. Notice Concerning The Americans With Disabilities Act (ADA) Amendments Act of 2008. U.S. Equal Employment Opportunity Commission; 2019. [https://www.eeoc.gov/laws/statutes/adaaa\\_notice.cfm](https://www.eeoc.gov/laws/statutes/adaaa_notice.cfm). Accessed September 26, 2019.
4. Family and Medical Leave Act. U.S. Department of Labor; 2019. <https://www.dol.gov/whd/fmla/>. Accessed September 26, 2019.