



The complexity of living with a rare condition, coupled with the physical aspects of XLH, can be overwhelming. Feeling different or not being able to do everything that your peers do can be frustrating and isolating. That's why it's important to pay attention to your mental health. There are many tools and supports that can assist you, including self-care, coping techniques, peer support, and reaching out for professional help. A mental health professional can be an important part of your care team.

## MAKING SELF-CARE A PRIORITY

Try to find a stress-reducing activity you enjoy and make it part of your regular routine, even when you're feeling well and life is not especially stressful. As you experience life's ups and downs, it's also important to know the **signs of depression** such as feeling sad, anxious, or "empty," having difficulty concentrating or sleeping, feeling restless and/or irritable, or feeling hopeless.<sup>1</sup>

These feelings are common and normal, but if they interfere with your daily activities, consider talking to your XLH specialist or primary care doctor. He/she may refer you to a mental health professional, such as a counselor, social worker, psychologist, or psychiatrist. After diagnosis, individual or family therapy, perhaps in combination with medication, can help you cope with symptoms of depression and anxiety.

## COPING TECHNIQUES

Coping techniques are tools to help manage stress and anxiety. They can be **emotion-focused** or **solution-focused**.<sup>2</sup> You can find techniques you can use on your own, or you may work with a therapist who can support and educate you about new ways of coping and behavior.

### Emotion-Focused Techniques

- Are used in situations that you can't (or don't want to) change
- Help people react less emotionally to stress



### Solution-Focused Techniques

- Are used in situations you can change, or change the way you handle them
- Try to eliminate or change the source of stress



## Working Through Challenging Emotions

One tried and true emotion-focused technique is **deep breathing**.

1. Take a deep breath and hold it for five seconds before exhaling slowly.
2. Repeat this several times until you feel more peaceful.

You can also try using meditation to help detach yourself from stressful thoughts. There are several free and paid mobile apps that guide users through meditation.

You may want to try changing the way you view a stressful or negative situation. For example, if you are feeling discouraged by a setback at school or work, try to reframe it as an opportunity to improve and shine next time. You could also reframe the setback as an obstacle to overcome, which is something most people need to do at one time or another, and then visualize yourself overcoming it and feeling great about it in the future.

Another coping strategy is doing something relaxing, like taking a hot bath, spending time with your pet, crafting, doing light exercise, or connecting with friends or your support group.

## Working Through Challenging Situations

Solution-focused skills encourage you to **think about your desired outcome, and then figure out the ways to get there**. You can think about the abilities and tools you've used successfully in the past to address a problem or consider a different way to approach it this time.<sup>3</sup> Try making a list of the things in your life that cause the greatest stress or biggest drain on your time and energy, and eliminate or change what you can.

Some situations, however, just can't be changed. You can't change the fact that you have XLH; nor can you lessen the amount of time it takes to get to class, or change the performance review process at work. But you can change how you handle these things. You can come up with creative ideas on your own, or work with a mental health professional to find solutions to a pressing problem.

Here are some examples of solution-focused coping techniques:

- When XLH makes it impractical to join your friends in their run training program, consider inviting them to go swimming or to join a tai chi group.
- Listen to podcasts or audiobooks or use driving time to do something else that makes you feel happy or productive – like catch up with friends or family on the phone. (Make sure you're using a hands-free device!)
- Talk to an occupational therapist about tips and tools you can use at home, work, or in a car to make those settings more usable, accessible, or comfortable for you.
- If you receive negative feedback about classwork or your performance at work, talk to your teacher or boss directly about what you can do differently. Remember that you have rights if you feel the negative feedback is connected to XLH or its physical limitations. See *the Navigating the Workplace section of this toolkit for more information*.

## MANAGING STIGMA AND BULLYING

Unfortunately, there can be still be stigma associated with disability and chronic illness. Often people make assumptions about what others with disabilities can or cannot do and **may not understand** the impact of a health condition like XLH. This misunderstanding may cause people to react negatively.

Here are some ways to combat bullying that occurs in-person at school or in the workplace:

- It's "old-but-good advice" – ignoring a bully is a good way to silence them. Bullies are looking for an emotional reaction. If you don't give them one, they may turn their attention elsewhere.
- Tell the bully to stop in a calm, non-emotional way – it can disarm them.
- There's safety in numbers. Sticking with a friend or group of friends can reduce the likelihood of being bullied.
- Educate them. Help reduce the likelihood of negative behavior by talking with your school or workplace about the best way to explain and educate your peers about what XLH is, and the impact it can have.

**Cyberbullying** – when someone repeatedly harasses, mistreats or mocks another person online or through text – is a serious problem for many people, whether they have a health condition or not. More than one-third of high school and middle school students report having been cyberbullied at some point in their lifetime, according to a national survey.<sup>4</sup>

Here are some strategies to combat cyberbullying:<sup>5</sup>

- Keep a record of what's happening. Take screenshots of the bully's attacks and hurtful posts whenever possible. When you're ready to report the bullying, it'll help to have documentation.
- Ask peers, friends, and mentors to intervene online by making positive posts to counteract a bully's negative or hurtful posts or shift the conversation in a more positive direction.
- Report it. Most social media platforms have clear policies for reporting cyberbullying and having offensive content removed. However, if you receive a threat of physical harm, report it directly to the police.



If you feel someone is bullying you, **ask for help**. When a student is being bullied at school, it may be necessary to speak to parents and/or school officials. When an employee is being discriminated against or exposed to bias at work, Human Resources may need to get involved. Even if you aren't ready to report, you should talk to someone you trust about what you're going through, so you don't have to face it alone. Also consider seeking support from a professional, such as a guidance counselor or mental health counselor.

## USING PEER SUPPORT

Connecting with others who share your experience can be helpful for people with rare conditions. This can be done in person, over the phone, or online through social media channels and email. Advocacy groups and forums like NORD ([rarediseases.org](http://rarediseases.org)), Global Genes ([globalgenes.org](http://globalgenes.org)), and Our Odyssey ([ourodysey.org](http://ourodysey.org)) connect people with all kinds of conditions and offer many resources and opportunities to meet others.

At the same time, the day-to-day life of someone with XLH can be unique. In a study of one rare disease community, participants valued connecting with others who shared their diagnosis.<sup>6</sup> There are disease-specific advocacy groups like The XLH Network ([xlhnetwork.org](http://xlhnetwork.org)), which hosts several events, as well as a Facebook page to connect and build community.

## DEALING WITH CRISIS

If you are thinking about suicide, or are worried about a friend or relative, call the suicide hotline for support. People are available to talk and help 24/7.

**1-800-273-8255**

[suicidepreventionlifeline.org](http://suicidepreventionlifeline.org)

## RESOURCES

### Global Genes

[Navigating Emotions: A Guide for Teenagers with Rare Disease](#)

### National Institute of Mental Health

[nimh.nih.gov](http://nimh.nih.gov)

### Anxiety and Depression Association of America

[adaa.org](http://adaa.org)

### National Alliance on Mental Illness

[nami.org](http://nami.org)

### Ditch the Label

(International Anti-Bullying Organization)

[us.ditchthelabel.org](http://us.ditchthelabel.org)

### Stop Bullying

[stopbullying.gov](http://stopbullying.gov)

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