

LIFE WITH XLH: TIPS FOR CAREGIVERS AND FAMILIES



Elizabeth and her son, Simon, living with XLH.

XLH (X-linked hypophosphatemia) is a hereditary, progressive, and lifelong condition which can significantly impact a person's daily life. People living with XLH may need help along the way from parents, spouses, family, friends, or caregivers. This resource provides tips and support to help people with XLH and their caregivers or care partners better manage their day-to-day and live well together.

THE IMPACT OF XLH

People who have XLH are usually short in stature and experience **fractures, chronic pain, and weakness in their bones and joints**. They may also experience **fatigue, trouble walking, muscle pain and weakness, hearing loss, and dental issues**.^{1,2} While there are common symptoms, it affects children and adults differently, and varies from person-to-person or even day-to-day.

XLHLink and The XLH Network have many resources, including **symptom information, support for children** living with XLH, and information about **finding an XLH specialist**. You can also check out the **Canadian XLH Network's Facebook page!**

"I'M A SCHOOLTEACHER AND THERE ARE DAYS I CAN'T EVEN OPEN A MARKER BECAUSE MY FINGERS HURT TOO MUCH. I SOMETIMES MAKE THE SMALL THINGS INTO GAMES FOR MY STUDENTS BECAUSE I JUST CAN'T DO IT."

- BESS, 35

Many people living with XLH have **a difficult time with daily activities such as handling groceries, opening containers, walking long distances, or going up and down stairs**. They may need assistance from a cane, walker, or wheelchair. Remember that XLH may get worse over time, so people with XLH can lose some independence as their physical abilities change.



Find others who are sharing their experiences with XLH at **The XLH Network**.

TYPES OF CAREGIVING RELATIONSHIPS

There are many different types of caregivers, and not every relationship is the same.

PARENTS OF CHILDREN WITH XLH

Learning to manage XLH together can be empowering for both parents and children who have XLH. Parents can download Self-care Assessments from the **XLH Transitions Toolkit**. Using these tools together will help parents gauge their children's understanding of XLH and help children take steps to manage their condition on their own.

Parents with XLH: Parents who also have XLH can play an instrumental role in teaching their children how to advocate for themselves and manage their health. Parents can also be good role models by taking care of their own needs.

SPOUSES AND PARTNERS

The task of managing XLH can feel daunting or intimidating, but good communication and understanding how the disease uniquely affects your partner, and what they need, can make it more manageable. For more about navigating XLH and relationships, check out the [Dating and Relationships](#) portion of the XLH Transitions Toolkit or the [Well Spouse Association](#).

“ACCEPTING IT IS THE HARDEST THING – NONE OF MY FAMILY IS WHERE I’M AT.”

– JUSTIN, 41

ADULT CHILD OF A PARENT WITH XLH

Adult children of parents with XLH can assist in continuous disease management by helping them advocate for themselves and make informed choices. Access the [Doctor Discussion Guide](#) on XLHLink.com to help ensure they are receiving proper care and are getting the most out of doctor’s appointments.



There are live and virtual events like conferences or webinars which connect families impacted by XLH and other rare conditions. Visit [UltraRareAdvocacy.com](#) to view upcoming events or check out the calendars on [XLHEvents.com](#) or [XLHNetwork.org](#) for XLH-specific events and more.

RESOURCES

- [Family Caregiver Alliance \(caregiver.org\)](#)
- [Angel Aid \(angelaidcares.org\)](#)

TAKE CARE OF YOURSELF, TOO

Helping someone manage XLH can be hard. According to research by the National Alliance for Caregiving, nearly **4 in 10 caregivers consider their situation to be highly stressful**, and 28% of survey respondents reported moderate emotional stress.³

Consider these tips for ways to deal with the stress that often accompany the day-to-day caregiving for someone with a chronic or serious illness

- **Find something that helps you relax.** Take a break, go for a walk, or find a few minutes for some deep breaths.
- **Keep up healthy habits.** Be sure to get enough sleep, exercise, get regular health checkups, and eat well to feel well.
- **Identify who can help.** Is there a close family friend or neighbor who wouldn't mind helping out with a couple tasks for an afternoon? If you're caring for someone older, respite care may also be a good option. Learn about it [here](#).
- **Speak with other caregivers.** Connecting with others in a similar situation can be an outlet – try joining support groups online or in social media. Check out The XLH Network's [Facebook page](#), the [Caregiver Action Network: 10 Tips for Family Caregivers](#), and the [National Alliance for Caregiving](#). If you live in Canada, visit [here](#) to access caregiver networks across the country.



Mental Health America has decision-making tools that might help identify your unique needs and places to find support: mhanational.org/self-help-tools. If you're Canadian, visit cmha.ca for additional mental health resources.

LIVING WELL TOGETHER

CHECKING IN

People with rare and chronic conditions are more prone to **experiencing anxiety and depression**.⁴ Be informed about the signs and signals, including withdrawal, sadness, inability to cope with daily problems or stress, major changes in eating or sleeping, and mood swings.⁵

People with XLH know that others may be making accommodations, and don't want to place additional requests on their family and friends. A good place to start is just by being there, being patient, and doing things that you know would show them you care. There's no need to be an expert – **the small things may go a long way**.

COMMUNICATION IS KEY

A good way for family members, partners, friends, or siblings and XLH-ers to foster healthy relationships is for everyone to practice active listening.

People with XLH can find it **difficult to explain or describe the pain** they are experiencing. They may also have a different scale or tolerance for pain since they may have been dealing with it their entire life. Try coming up with a system of signaling pain level with one another. See a sample pain scale in this [Doctor Discussion Guide](#).



Tip: Use "I" statements.
Rather than "You are...", use "I am worried about you"⁶

MANAGING DAILY LIFE

Sometimes navigating life with a rare condition can mean **thinking outside of the box**. Be prepared to find and make accommodations within the home.

“I CAN’T GET IN A SHOWER OR BATHTUB. THERE ARE THINGS YOU HAVE TO DO TO ADAPT YOUR ENVIRONMENT. AT MY HOUSE, THERE ARE NO STAIRS GOING FROM THE MAIN HOUSE TO THE CAR OR GARAGE. THERE ARE NO UPPER CUPBOARDS IN THE KITCHEN BECAUSE I CAN’T REACH.”

– CONNIE, 55

Below are a few easy and cost-effective ways to make your home more accessible:

- **Place handrails** in key areas, such as near the toilet and shower/bath
- **Add grips** to the floor of the shower/bath
- Select **appliances shorter in height** (i.e. a shorter fridge or a lower table)
- Store pots, pans, and utensils in **lower cabinets**
- Ensure **flooring is level** (and not too slippery or too rough to move wheels on)
- **Spread out furniture** in key common areas such as the kitchen or living room
- Consider getting **pedal extenders** to make driving easier

If it’s possible or you have time to plan, consider living in a one-floor home or an apartment with elevator access and request or look for an apartment close to the elevator.



Additional tips @ *The Mighty's* [list of Smart Home devices](#) for people with disabilities.

It’s common that XLH-ers need more time and a plan to get ready for an event, for school or work, or just to go run errands. Keep an organized schedule with extra time built in. Be realistic – don’t overbook or choose something that may be too physically strenuous. It’s important to keep special situations in mind, such as planning a family vacation or navigating an emergency together.

RESOURCES:

- [Traveling with a Disability](#)
- [Rare & Prepared: Emergency Planning for Individuals with Complex Healthcare Needs](#)

SIBLING DYNAMICS

Being a sibling of someone with a rare disease can be **scary** and **frustrating, as well as rewarding**. Siblings of people with rare disease may grapple with feelings of stress and worry.⁷ It's common to feel isolated or like their problems aren't as important. **They may also be taking on responsibility for their sibling(s)** or want to be involved in their care.⁸ To help balance family, school, responsibilities, and friendships, try creating a schedule for both siblings and stick to it – remember to factor in the extra time a person with XLH might need. These strategies may help siblings of someone with XLH feel less overwhelmed and more prepared. Finding an outlet for complex emotions, such as talking with a friend, journaling, or making art, can be helpful as well. For more information, listen to the Global Genes podcast on “[The Psychological Toll Rare Diseases can Have on Healthy Siblings.](#)”



To help children better communicate and manage their feelings, parents can dedicate special time each week to spending quality one-on-one time with each child – cue up a movie or play a board game together.

“NOBODY HAS THE SAME STORY, BUT I HOPE SIBLINGS OF THOSE WITH RARE CONDITIONS WILL TAKE COMFORT IN KNOWING THEY ARE NOT ALONE.”

- MARAH

RESOURCES

- [The Sibling Support Project \(siblingsupport.org\)](#) - check out their **SibShops**, too!
- [Siblings with a Mission \(siblingswithamission.org\)](#)

REFERENCES

1. Linglart A, Biosse-Duplan M, Briot K, et al. Therapeutic management of hypophosphatemic rickets from infancy to adulthood. *Endocr Connect.* 2014;3(1):R13-30. **2.** Gaucher C, Walrant-Debray O, Nguyen TM, Esterle L, Garabedian M, Jehan F. PHEX analysis in 118 pedigrees reveals new genetic clues in hypophosphatemic rickets. *Hum Genet.* 2009;125:401-11. **3.** AARP and National Alliance for Caregiving. Caregiving in the United States 2020. May 2020. <https://doi.org/10.26419/ppi.00103.001>. **4.** EURORDIS. Juggling care and daily life: the balancing act of the rare disease community: a Rare Barometer Survey. May 2017. **5.** Mayo Clinic. Mental illness: Symptoms & causes. Mayo Clinic Website. Published June 08, 2019. Accessed July 14, 2020. <https://www.mayoclinic.org/diseases-conditions/mental-illness/symptoms-causes/syc-20374968> **6.** American Psychiatric Association. Helping a Loved One Cope with a Mental Illness. American Psychiatric Association Website. Accessed July 15, 2020. <https://www.psychiatry.org/patients-families/helping-a-loved-one-cope-with-a-mental-illness>. **7.** Haukeland Y, Fjermestad K, Mossige S, Vatne T. Emotional Experiences Among Siblings of Children With Rare Disorders. *J. Pediatr Psychol.* 2015;40(7):712-720. <https://doi.org/10.1093/jpepsy/jsv022>. **8.** Smith J. Eight things siblings of children with special needs struggle with. The Washington Post. Published December 20, 2016. Accessed July 15, 2020. <https://www.washingtonpost.com/news/parenting/wp/2016/12/20/8-things-siblings-of-children-with-special-needs-struggle-with/>