

Fill out this form before visiting your doctor. Be as honest as you can. There are no right or wrong answers. This will help you understand your level of preparedness for taking over your own healthcare as an adult. If you answer “I don’t know / do this yet” to any of these questions, review them with your doctor.

How important do you think it is to learn about managing your own healthcare, where 1 is least important and 10 is most important? Please circle one.

1 (least)	2	3	4	5	6	7	8	9	10 (most)
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XLH KNOWLEDGE

	I feel comfortable with this	I am still learning this	I don't know/ do this yet
I know what XLH is and how it affects my body.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain the common symptoms of XLH to another person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand what “phosphate-wasting” means.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what kind of XLH I have (spontaneous, inherited).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how I was diagnosed with XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the tests I should receive and how often to monitor XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to read and interpret my lab test results.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how XLH can be passed down in families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can find my medical history (such as dates and types of surgeries, family history, allergies, and medications).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how XLH symptoms may change over time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This is how I explain how XLH is passed down in families: _____

For more information about XLH, including symptoms, inheritance pattern, and management, read the “Learn more about X-linked hypophosphatemia (XLH)” educational brochure in this toolkit.

SELF-CARE

	I feel comfortable with this	I am still learning this	I don't know/ do this yet
I know my current XLH treatment plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain my treatment plan to a doctor or nurse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the consequences of not taking care of XLH.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my medication schedule and what to do if I miss a dose.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to recognize and talk to my doctor about new symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I stick to my medication schedule without someone reminding me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the potential side effects of my medication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what medications I should not take and what medications I am allergic to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my emotions with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand where to go for help and support for my mental health, like if I feel depressed or alone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand what accommodations might be available to me at college or in the workplace.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know about assistive equipment that might help me in the future and where to find it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand what XLH means for my reproductive health and starting a family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This is where I can go for help and support: _____

USING HEALTHCARE SERVICES

	I feel comfortable with this	I am still learning this	I don't know/ do this yet
I know my doctors' names and contact information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how frequently I should be seen, I make my own doctor appointments, and keep track of them on my calendar.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I go to my appointments without my parent or caregiver.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am prepared to make decisions about my own care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I come to my doctor appointments prepared with questions and ready to talk about my current issues or concerns.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know to ask for an explanation when I don't understand something my doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I may need to seek out specialty healthcare providers for new or different symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do in case I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill and refill prescriptions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can provide a summary of my medical history (such as dates and types of surgeries, family history, allergies, and medications).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms or where to get help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry my important health information with me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my health insurance information (plan, coverage).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I may have to get my own health insurance and where to find it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This is where I would look for health insurance: _____

How confident do you feel about your ability to manage your own healthcare, where 1 is lowest confidence and 10 is highest confidence?

1 (lowest)	2	3	4	5	6	7	8	9	10 (highest)
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When I think about my health in the future, I wonder about: _____

When I think about my future, these are the things I want to do: _____

When preparing for your next doctor visit, keep the following questions in mind:

- When I meet with my doctor, what do I want to discuss?
- What do I want to get out of this appointment?
- What do I really need or want to know?

NEXT STEPS

You can start or continue the pediatric to adult care transition discussion with your doctor by asking:

- Can you recommend any adult specialists who might be knowledgeable and willing to care for XLH patients? If not, are you aware of any primary care providers who specialize in caring for adults with complex health conditions such as XLH?
- Are you open to having a shared visit with the new adult doctor? If not, are you willing to contact the new adult doctor before our first visit? *See the Transfer of Medical Care Letter Template in this toolkit as a reference.*
- How will my medical records be sent to the new doctor?



Download the full **XLH Transitions Toolkit** at **XLHlink.com**