

Fill out this form before visiting your doctor and review it with your parents. Be as honest as you can. There are no right or wrong answers. Your answers will help you create a plan for when you turn 18 and take over responsibility for your own care. You can fill out this form once a year and see how your answers change. You may also want to bring it to your next doctor visit.

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 know how to talk to my teachers or employer about needs I may have in the classroom or work environment.	<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 during my doctor visits and how often to monitor XLH symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what kind of XLH I have (spontaneous or inherited).	<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 (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"/>

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 am comfortable with 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 when I'm supposed to receive my medication (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 are available to me for my education (e.g., 504 Plan) and what that means.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know about assistive equipment like canes, crutches, and walkers, that might help me in the future, and where to find them if I need to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand what XLH means for starting a family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have discussed my ability to make my own healthcare decisions with my parents or caregivers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how my rights will change when I turn 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 make my own doctor appointments and keep track of them on my calendar.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel comfortable speaking to my doctor and asking questions without my parent or caregiver.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am preparing to make decisions about my own care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do in case of a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get to my doctor(s) office(s) without help.	<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 talk to other types of doctors for my symptoms as I get older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can provide a summary of my medical history (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 doing so.	<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 that I will eventually be unable to continue under my parents'/caregiver's health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 future, these are the things I want to do:

If you answered "I don't know / do this yet" to any of these questions, review them with your parents, other family members, or your doctor. You can also refer to the **Doctor Discussion Guide** in this toolkit to help you better discuss your health and symptoms during your doctor appointments.

NEXT STEPS

It is likely that when you turn 18 you will have to change to an adult doctor. You will also have to give your parents' permission to be in the room during your doctor visits and to hear your personal health information starting when you turn 18. You can begin or continue the transitions discussion with your doctor by asking:

- When do you recommend I start to see you alone for a portion of these appointments?
- Does your office have a template for a medical transition plan?
- Can we review our transition plan with you on a yearly basis?
- Can you recommend any adult specialists who might be knowledgeable and willing to care for 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**