



Talking to your doctor isn't always easy. You may not have a lot of time during the appointment, and it can be hard to explain exactly what's wrong. If you're not prepared or unsure where to start, you may leave the appointment dissatisfied and without the answers you need. Filling out this Doctor Discussion Guide prior to your appointment can help you get the most from your doctor visits. It is designed to help you start the conversation about symptoms, challenges, questions, and concerns you may face on a daily basis as someone living with XLH.

Think about why you scheduled your doctor's appointment. Then ask yourself:

- 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?

MY XLH EXPERIENCE

I am experiencing the following symptoms: (check all that apply)

- Bone pain
- Joint pain
- Muscle pain
- Pain in a specific area or body part(s): _____
- I have pain, but I'm not sure what kind
- Joint stiffness
- Limited range of motion
- General muscle weakness: _____
- Muscle weakness in a specific area: _____
- Tooth abscesses/dental issues
- Fatigue/exhaustion
- Hearing impairment/ringing in ears (tinnitus)
- Balance changes/feeling dizzy or off-balance (vertigo)

I experience pain: (circle one)

Most of the day Some of the day During activities

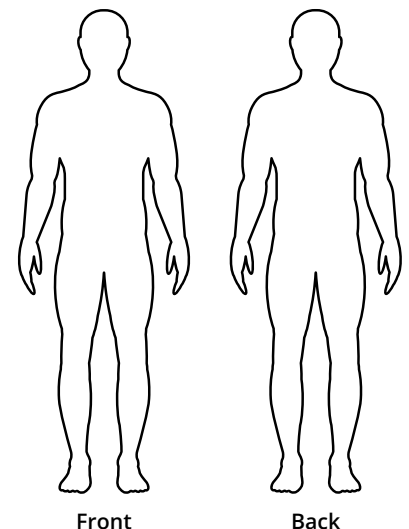
My pain is typically worse: (circle one)

Mornings Mid-day Evenings During sleep It lasts all day

How would you rate your worst pain level recently? Below is a typical pain scale doctors may use. Pain can be difficult to explain. It might be helpful to ask your doctor for a referral to a pain specialist.

0	1	2	3	4	5	6	7	8	9	10
No Pain	Very Mild	Minor	Noticeable	Strong	Piercing	Intense	Very Intense	Horrible	Excruciating	Unimaginable

Mark on diagram where symptoms occur:



Some of these symptoms are new or have recently changed: (provide an explanation below)

When I walk, I find myself needing support, or assistive equipment: (circle one)

Not at all Sometimes Most of the time All of the time

I typically use (e.g., a cane, crutches, the wall, hand rail):

I'm struggling with: (check all that apply)

- Doing daily activities
- Walking up and down stairs
- Sleeping
- Exercising
- Feeling depressed
- Feeling anxious
- Other: _____

I am concerned about: (check all that apply)

- Getting older
- The progression of my disease
- Starting a new job
- Going to college
- Starting a relationship
- Starting a family
- Getting health insurance
- What my health insurance covers
- How to find a specialist
- Other: _____

I would like more help with, or information about:

When I think about my health in the future, I am most concerned about:

ACTION PLAN

My doctor and I decided on these next steps:
