

# Talking to your family about XLH

*The quotes provided throughout this document are based on the experiences of real people living with XLH. Their names have been changed to protect their identity.*



# Who is this leaflet for?

This leaflet is intended for people diagnosed with XLH who want to discuss their condition with their family. By the end of this leaflet, you should have a better understanding of who to involve, what to talk about and how to prepare for this kind of conversation.

# Starting the conversation

Talking about XLH could make all the difference in helping those close to you who may have XLH to seek appropriate medical support.

Family mapping is an essential tool to find out which of your relatives could be at risk of also having XLH, but the topic might feel difficult to talk about.

Here you'll find some advice and tips to help you prepare and make those conversations more comfortable for you and your family. You can also read about the experiences other people have had discussing XLH with their family, and the impact an open conversation had for them.



# How do I prepare?

## **Think about who to include**

While it's important for every family member to be aware of XLH, not everyone will benefit from the same type of conversation.

## **Think about how you want to start the discussion**

You may want to send a text message or email to family members who you do not have close contact with, have one-to-one chats with others and maybe even plan a sit-down conversation with your closest family members.

Explaining the inheritance pattern of XLH using family mapping can help your family understand why they are being involved. The "What you need to know" leaflet has useful information to guide your explanation. Let them know that it could be in their best interests to get tested, just in case.

- **Think about who you need to speak with**
- **Think about what method of communication is most comfortable for you and your family members**
- **Consider using the message outline overleaf to help you write to family members, or write your own**

# Message outline

Here are some ideas of the key points to include in a message to your family:



Begin by telling them about your diagnosis.



Explain what XLH is and what some of the symptoms are.



Tell them that the condition is genetic, which means they might be affected, even if they have no symptoms.



Explain the family mapping process – it ensures that people who might be affected by XLH are aware and can seek the care they might need.

Opening up a dynamic conversation about the inherited nature of XLH is essential to help your family understand why they are involved in your diagnosis.

Be prepared to answer their questions but don't feel that you need to be an expert on your condition. This leaflet includes helpful resources that you can share with your family throughout the process.

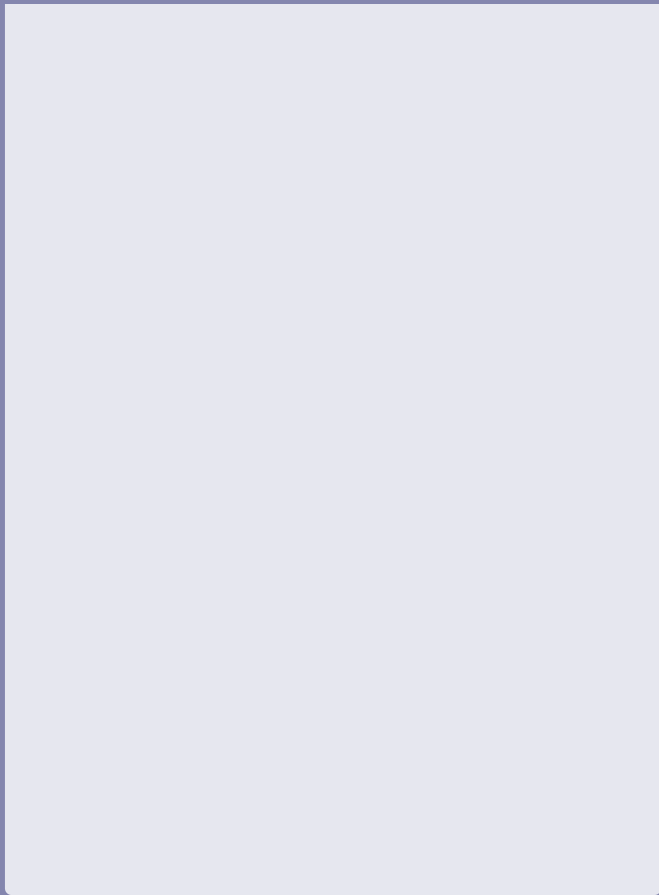
# Katie's experience

Katie was diagnosed with XLH when she was 2 years old. Her parents noticed that her legs were growing abnormally and weren't aware of XLH. Katie's father thought of his grandmother, who he knew had similar symptoms. Because of the lack of information and communication in the family, the diagnosis came as a shock. Only later did they confirm that the condition had been present in the family for generations.

Nowadays, the family always arranges for XLH testing when a baby is born and have conversations about how it has passed down through generations. This has helped them understand how it is inherited. Katie feels that family mapping gave her a head start to understand the condition and how it could affect her.



## Notes



# Planning a family meeting could make things easier

Planning a family meeting on the weekend will allow most family members to attend and give everyone some time to prepare for the conversation.

The conversation should ideally be a balance of explaining the physical impact of XLH and a discussion of the psychological impact this will have on you and your family.

Think about anything else you would like to include to make the conversation as comfortable as possible.

## **Advice**

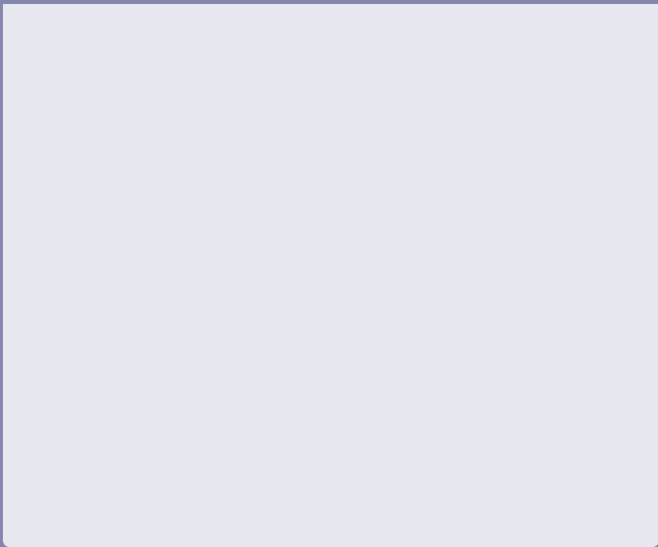
If you have any questions or concerns, make a note of them. Speak to a healthcare professional before talking to your family about XLH, so that you can go into the conversation feeling confident and ready.



# Talk to children separately

If you decide to include children in the conversation about family mapping, you may want to consider having one separately with them. Children may have more questions and setting time aside for a simple talk with them might be easier than involving them in a wider family discussion.

## Notes



# Bring materials with you to the discussion

Some family members may not fully understand XLH and other relevant information the same way as you. Whether you have one-to-one meetings or family gatherings, bringing relevant leaflets will help you go through the important things together and answer questions the family may have about living with XLH and family mapping.

## Useful things to bring with you



The  
“What you  
need to know”  
leaflet



Your  
conversation  
plan (overleaf)



A completed  
family map if  
you already  
have one



Any other  
resources that  
help you feel  
confident talking  
about XLH

If you have access to the internet, you could look through the <https://www.xlhlink.asia/> website with your family members. This contains useful information about the inheritance pattern of XLH.

# Matthew's experience

Both Matthew and his daughter have XLH. He reflects on his experience with the condition and finding out relatively late. He has managed to help his daughter avoid the stress and lack of clarity he went through by holding conversations with his partner and making testing a priority for planning a family.

*"Getting the genetic tests done was what really told us specifically what is going on. My own experience was that throughout childhood they thought I may have rickets inherited from my mother, but there was no genetic proof for anything. Looking back at my experience, I would have liked to have more detailed information about how my health and that of my family would be affected, and how my illness has come about."*

## Notes

# Make a plan to guide conversation

Having a difficult conversation means that we sometimes forget all the topics we want to cover. Consider using this conversation plan and add your own topics to help you keep track of your conversation.

Notes



# Conversation plan

- Read out your conversation plan so that everyone has a chance to prepare
- Read the “What you need to know” leaflet together and the family mapping section
- Discuss how family mapping can be beneficial for your family
- Ask your family about how XLH has affected them and others
- Ask your family if they have any questions or concerns
- Allow every family member to respond and write down any questions you can't answer
- .....
- .....
- .....

## Sofie's experience

*“There are several generations and several people in the family with this disease. In the beginning, my family didn't like talking about XLH. It seemed the topic was avoided. When we decided to do family mapping, it became more normalised. It is a normal thing for us now, and everyone now speaks about it. If anyone in my family feels like they need to ask or say something, they can, but often people think it will bother others. Personally, I believe that families should be able to talk openly about this and have a normal conversation about it.”*

## Deciding if you're ready

Starting a conversation with your family around XLH is the first step for family members to seek diagnosis for XLH should it be needed.

But it's important that you feel ready and comfortable talking about the topics you need to cover. Consider using our 'conversation readiness' scale and examine step-by-step how confident you feel talking to your loved ones about family mapping:



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graph LR; A[I understand what family mapping is and how it will help my family] --- B[I have read the information on this website and/or the family mapping leaflets]; B --- C[I have information and materials that I can share and use to answer any questions]; C --- D[I know who to speak to if I have any questions]; D --- E[I have downloaded the conversation checklist and added my own]; E --- F[I have rehearsed the conversation in my mind]; F --- G[You're now ready!];
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I have read the information on this website and/or the family mapping leaflets

I know who to speak to if I have any questions

I have information and materials that I can share and use to answer any questions

I have downloaded the conversation checklist and added my own

I have rehearsed the conversation in my mind

**You're now ready!**

# Helpful resources

XLHLink.asia website  
<https://www.xlhlink.asia/>