

KKI/INT/KKI/1097 June 2025

This map was developed and fully funded by Kyowa Kirin International.





Adolescents with X-linked hypophosphataemia (XLH)

At a time when most young people are trying to assert their independence, adolescents with XLH can find themselves increasingly in need of physical and emotional support from their caregivers and their healthcare team. Using insights from patient interviews, surveys and desk research, here we explore the particular impact of XLH on adolescents as they prepare to transition to adulthood.



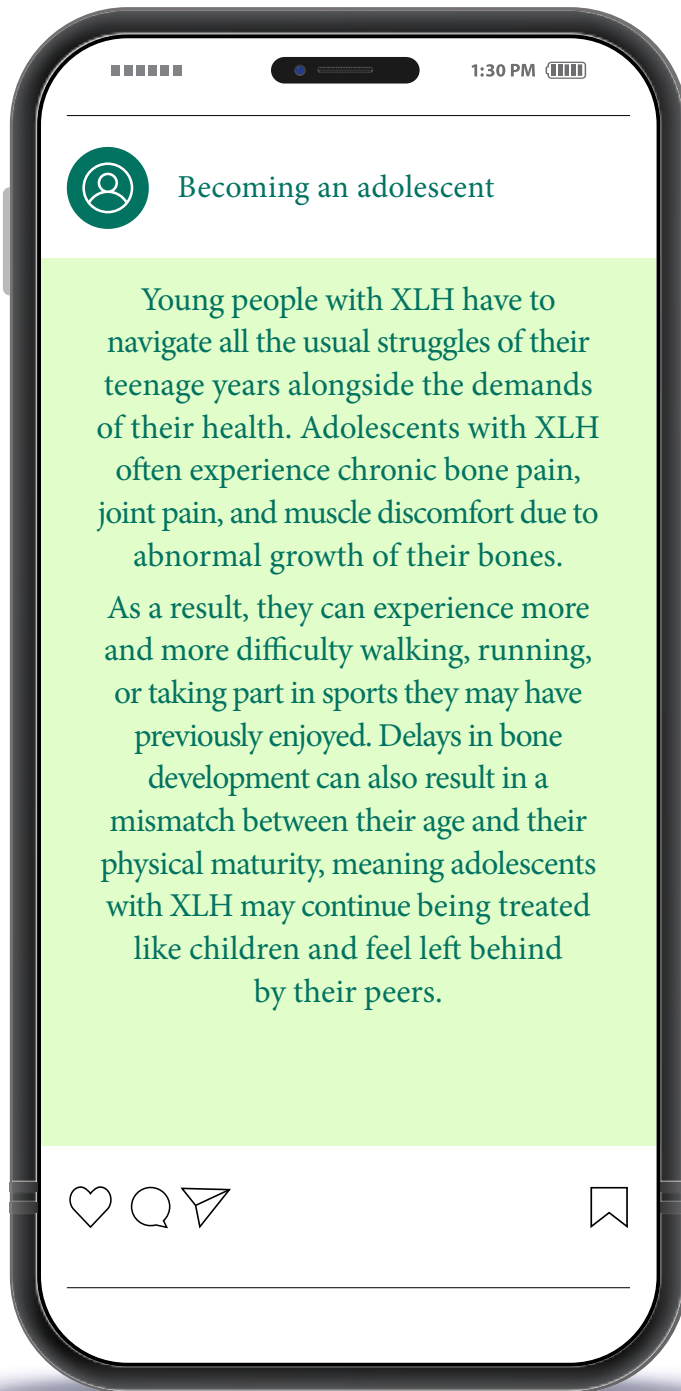
Start here

Becoming an adolescent

Life with XLH

Transition

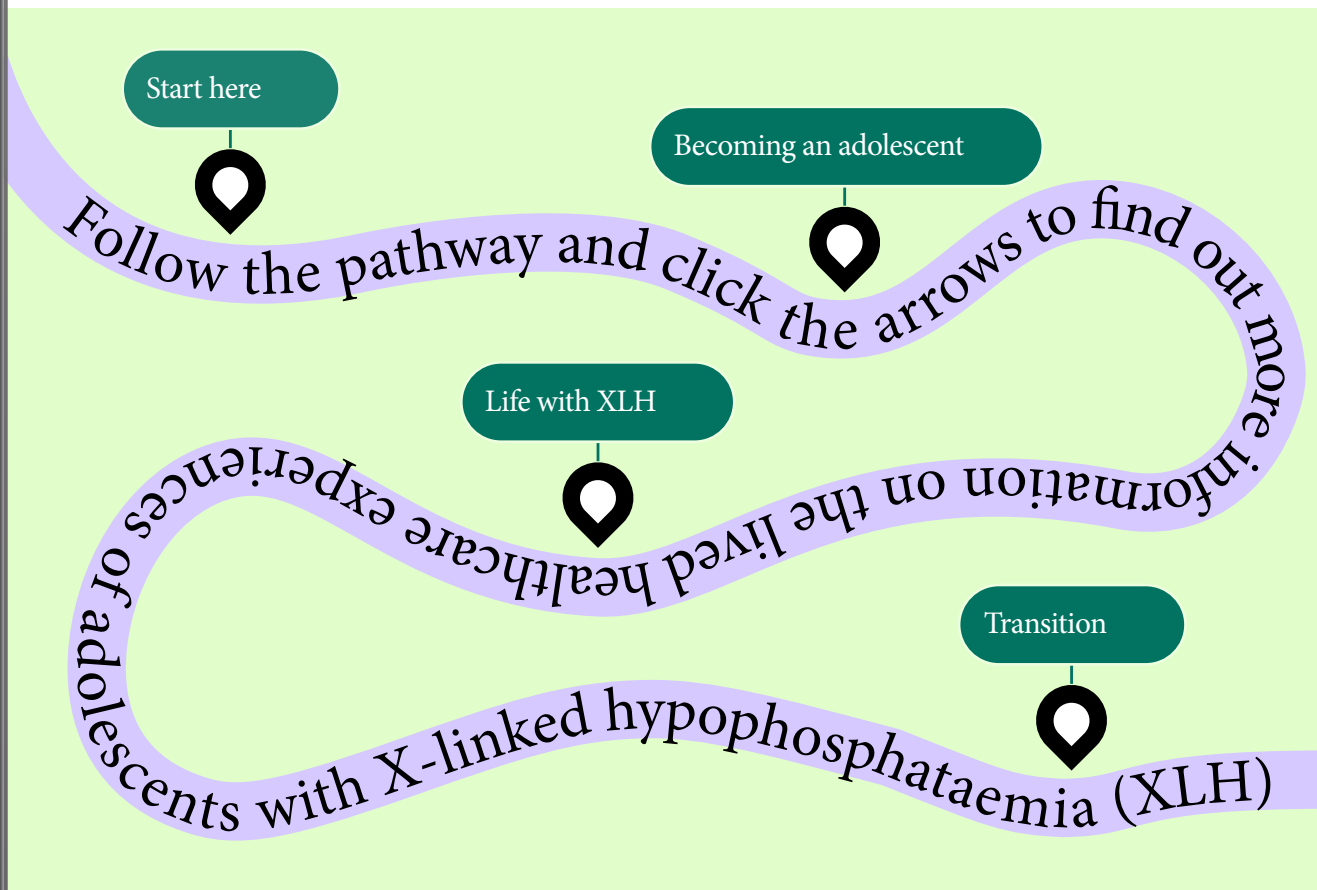
Follow the pathway and click the arrows to find out more information on the lived healthcare experiences of adolescents with X-linked hypophosphataemia (XLH)



Becoming an adolescent

Young people with XLH have to navigate all the usual struggles of their teenage years alongside the demands of their health. Adolescents with XLH often experience chronic bone pain, joint pain, and muscle discomfort due to abnormal growth of their bones.

As a result, they can experience more and more difficulty walking, running, or taking part in sports they may have previously enjoyed. Delays in bone development can also result in a mismatch between their age and their physical maturity, meaning adolescents with XLH may continue being treated like children and feel left behind by their peers.



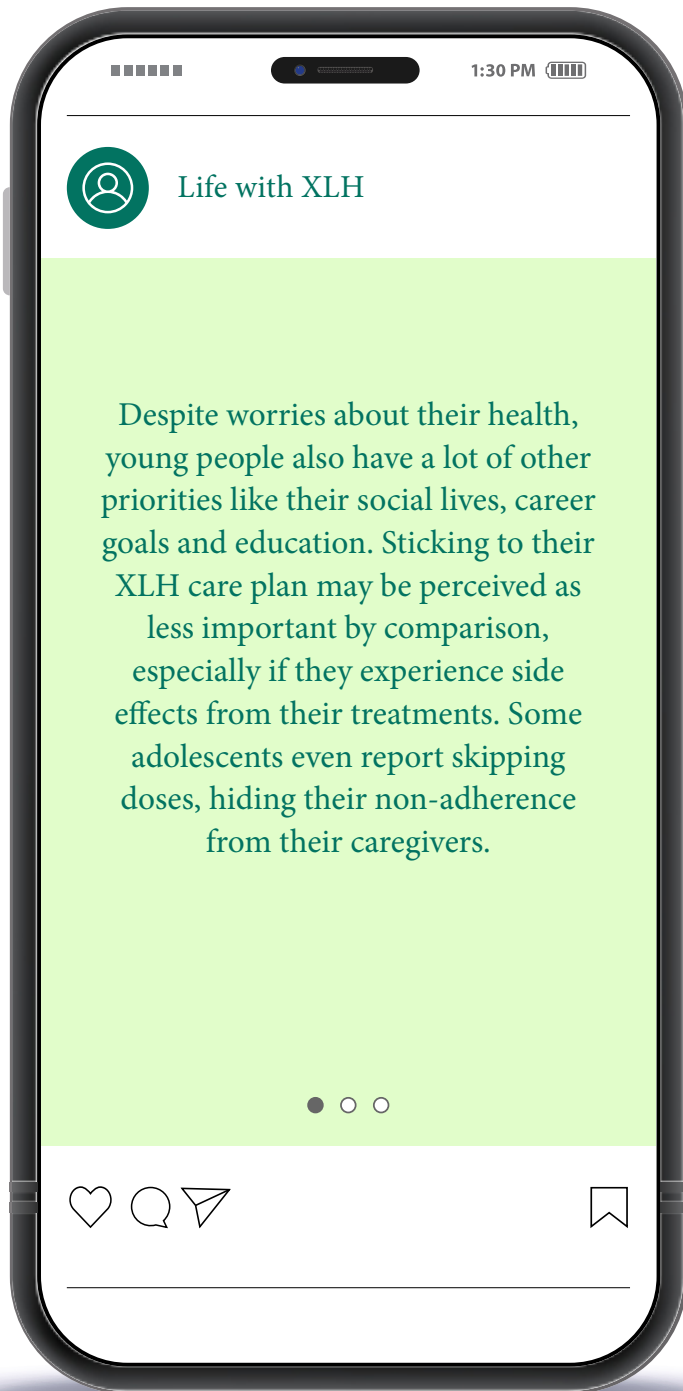
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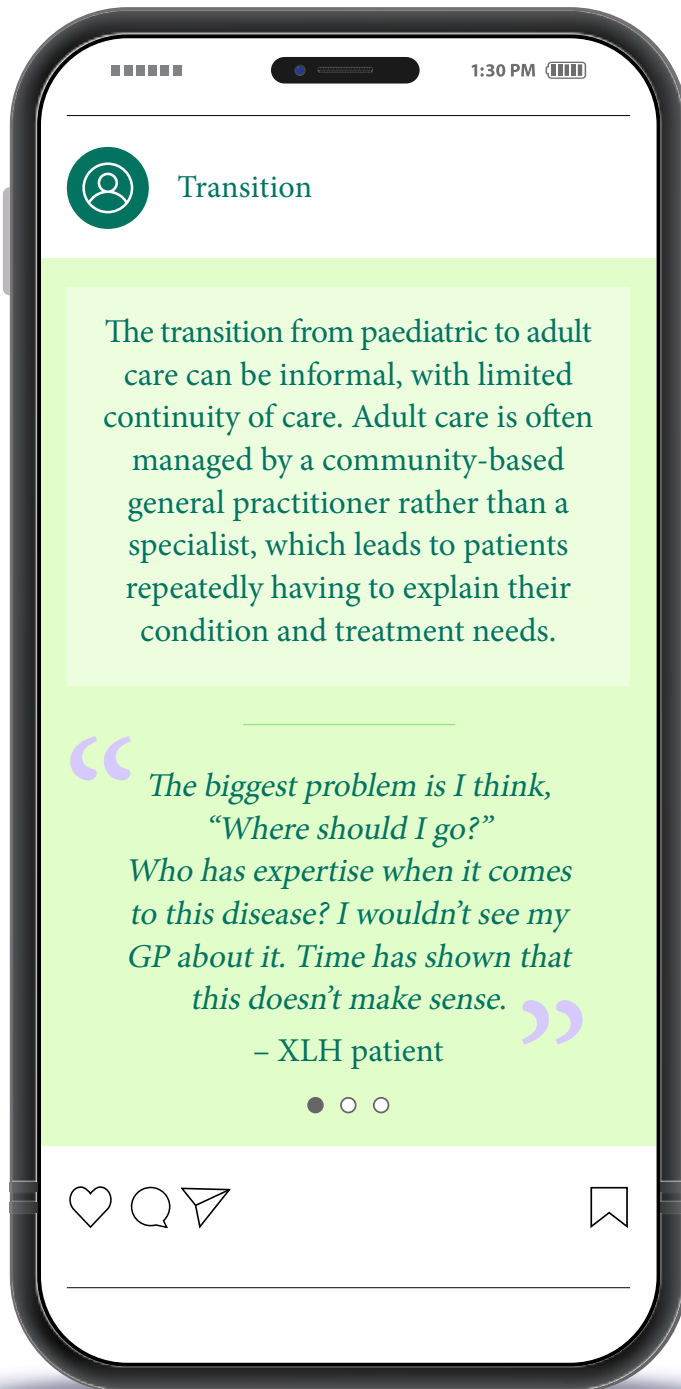
Life with XLH

Despite worries about their health, young people also have a lot of other priorities like their social lives, career goals and education. Sticking to their XLH care plan may be perceived as less important by comparison, especially if they experience side effects from their treatments. Some adolescents even report skipping doses, hiding their non-adherence from their caregivers.

This is also a time when young people become more aware of their appearance, which can result in feelings of social isolation for people with XLH who have very visible symptoms. For some, the realisation that they may have reached their full adult height in their teenage years can be very upsetting.



Given the emotional challenges of puberty and young adulthood, coping with ongoing treatment, pain, and social limitations can be intensely distressing and heighten their risk of anxiety and depression. Adolescents also have significant worries about the future, such as the potential for mobility issues in later life if their bone health continues to get worse.



Transition

The transition from paediatric to adult care can be informal, with limited continuity of care. Adult care is often managed by a community-based general practitioner rather than a specialist, which leads to patients repeatedly having to explain their condition and treatment needs.

“The biggest problem is I think, “Where should I go?” Who has expertise when it comes to this disease? I wouldn’t see my GP about it. Time has shown that this doesn’t make sense.”

– XLH patient

While the clinical manifestations of XLH in children are fairly well understood, new debilitating symptoms can emerge in adulthood that patients feel unprepared to manage. The lack of information and limited awareness among physicians can lead patients to rely on the internet for education, or to discontinuing care entirely.

“Paediatric patients are attended by specialised centres for a number of years. Then after having built up friendships, bonds and trust with the doctors, when they have to move on to adults, they abandon everything...”

– Rheumatologist

“It’s a big thing, isn’t it, when you go from being in this nice cosy hospital with lots of children focused and they used to treat the children as children. Then suddenly going into an adult clinic, which is full of grown-ups, when you’re only a young adult yourself”

– XLH Patient

“Changing to adult care wasn’t easy and we’re still struggling”

– XLH caregiver