

Here to help

It doesn't matter what stage of your life journey you are at, we are here to help



the early days

Receiving a diagnosis can be a devastating time for families and can feel a very lonely. If you need a friendly voice to chat to, someone who knows how you feel, just reach out - we are here to catch you.



financial planning

A diagnosis of XP can have a huge financial impact on families. Get in touch to find out about benefits and grants you may be entitled to to help safeguard your families financial future.

dealing with change

Life brings many changes and sadly this can mean changes in your/your child's health. This can be difficult to process. Being connected with others who have walked this path can help. We can help make these important connections.



making adjustments

Living with XP can make you feel vulnerable especially in those early days. Making your immediate home and lifestyle UV safe is a high priority to help ease additional anxieties. We can help with lots of practical advice on how to make the necessary adjustments, including free UV protective visors, gloves and home protection grants (*).



living your best life

See our action advice hub for top tips and advice on how to live **your** best life and the links and tools to help you thrive with the new norm of life with XP.



coping with loss

Coping with the loss of a loved one is never easy and can need dedicated support. Reach out for signposting to services that can help you acknowledge and navigate your grief.



the school years

Navigating the school years for a child or young adult with XP can be challenging. See our schools hub for resources to share with your school.

finding your tribe

As an ultra-rare disease it can feel isolating not having peers who understand your challenges. Connect with us so you can find your tribe and learn more about the events we run to keep us all connected.

