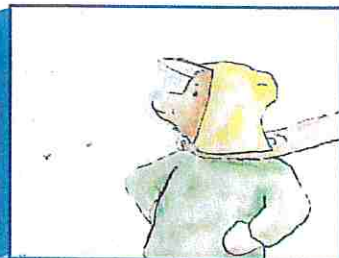


Little Ted's Guide to XP (Pupil)



What is XP?

XP stands for *Xeroderma Pigmentosum*. It is a very rare condition affecting less than 100 people in the United Kingdom and between only 1000-2000 in the whole world!

For people who have XP, being exposed to daylight and light bulbs which emit ultra-violet light is very harmful to their skin and eyes, and this damage cannot be repaired. Sometimes people with XP have other difficulties with hearing, eyesight, balance and learning but only 30% have some or all of these problems.

Who has XP?

People with XP are born with it. XP is a genetic condition which means that it is inherited from our parents in the same way as eye colour and other characteristics.


What does having XP mean?

Having XP means that you must always be protected fully from daylight and any harmful light bulbs. To achieve this, a number of things can be done:

- Wear special UV blocking clothing to cover all areas of skin, including hands and face when outside;
- Apply special UV blocking film to home, school & car windows to make them safe;
- Replace light bulbs with UV free bulbs or put diffusers over them to make them safe;
- Not going outside on warm days to avoid over heating in special clothing.

Having XP also means attending regular hospital checkups with a special XP Doctor to make sure that they are keeping safe and well. This includes checks on the skin, eyes, hearing and movement.

Having XP means that some activities are limited or restricted but it does also mean that you get to have extra late nights, to enjoy playing outside after dark when the sun's UV has gone!

 Please turn over

Little Ted 

How can I help someone I know who has XP?

How can I help others around me if I have XP?

Be patient and take the time to explain your needs to your friends and others around you so they can understand how to help keep you safe while having fun!

Just like wearing glasses, or being tall, feeling or looking a little different can be very difficult, so remember just like these differences, people with XP are really exactly the same as you! Here are some other ways you can help:

- Help them keep windows and doors closed;
- Think carefully before turning lights on "are they safe?"
- Be careful with other sources of light found in toys, torches etc;
- Make sure they keep their protective hat and gloves on when outside playing.

Frequently Asked Questions

- **Does having XP hurt?** If a person with XP is exposed to unsafe UV light it can burn their skin and make it sore. Also wearing their protective clothing can be uncomfortable;
- **Can a child with XP come to my house, is it safe?** Yes, most things are possible with a little pre-planning;
- **Is there a safe time for people with XP to be outside unprotected?** Yes, generally when it is dark outside, before sunrise and after sunset;
- **Why do some people with XP have freckles?** This is damage to the skin caused by exposure to UV.

