

When a child with xeroderma pigmentosum (XP) is starting at your school

This leaflet aims to give teachers more information about xeroderma pigmentosum (XP). It offers guidance on how to assess and adapt the school environment before the child starts school. It also outlines the general support needed by all children with XP. Children with XP are affected by their condition in different ways, so to understand more about the child coming to your class we recommend talking to his or her parents before he or she starts school. If you have any questions or concerns, please get in touch using the contact details on the back page.

What is XP?

XP is a rare, hereditary skin condition where the body is not able to repair damage caused by the ultraviolet (UV) part of daylight. People with XP are more likely to get sunburnt or develop abnormal freckles on skin which is exposed to daylight. They can also develop eye problems due to damage from ultraviolet light. People with XP are more likely to develop skin cancers, particularly if they do not protect themselves from the harmful effects of ultraviolet light. XP can also cause problems with the nerves or brain.

Since XP only affects one in 250,000 people it is very unlikely that you will already have any knowledge of the condition. You may want to find out more from the child's parents, an XP clinical nurse specialist, the child's consultant, the XP Support Group or the local community nurse.



Children with XP:

- Need to be kept away from all unprotected sources of UV light (see page 2)
- Need to wear visor, gloves, long sleeves and hat when near any unprotected source of UV light (see photo below and page 3)
- Need to apply factor 50+ sunscreen regularly (see page 3)

A young boy with XP wearing a UV protective visor.

What factors do I need to consider before a pupil with XP joins the school?

With the right support, children with XP attend regular schools and are educated alongside children of their own age. However, it is important to put aside time to plan and make any changes that may be needed to the school (see below).

Some children with XP may need a special educational needs assessment – you can find out more about this at www.directgov.co.uk or download a leaflet from www.teachernet.gov.uk/publications

Arranging a visit from the XP clinical nurse specialist

Many teachers find it helpful to have a visit from an XP clinical nurse specialist to find out more about the condition and any preparations needed before the child can join the school.

Making the school environment as safe as possible by assessing and reducing sources of UV light

In order for the child to attend lessons in a safe environment away from identified sources of UV light, there needs to be careful planning. Many teachers find it helpful to walk around the building following a timetabled day for the pupil with XP, identifying any risks. You may find using a UV meter helpful and the XP nurse specialist can discuss this with you. You may also want to consider changing classrooms or timetables to avoid potential UV exposure.

High risk: Windows and door panels

- UV light can travel through glass.
- Glass may need to be covered with UV filter that will not affect the visible light levels in a room. Various companies offer this protective film, but the XP clinical specialist can advise you if you need help. Some modern windows incorporate a UV filter at source.
- If you are unable to cover the glass with a protective film, then the further the child sits away from the source, the lower the risk of damage from UV light.
- Consider using blinds as a substitute to UV protective film.
- Windows should be closed. If the classroom is at risk of overheating, consider installing air conditioning or fans.

Potential risk: Light bulbs

- Certain types of light bulbs can emit some UV..
- Incandescent bulbs are considered low risk, as are LED bulbs.
- Compact fluorescent and fluorescent strips can pose more of a risk. these should be covered with either a protective sleeve or encased in a protective case.
- Halogen bulbs should be avoided.

Low risk

Computers, photocopiers, and white boards are all low risk so no changes are required.

Getting to and from school

- Some children with XP are eligible for school taxi to the school door, to limit their time outside. The taxi should have tinted windows or be protected by UV window film.

- If the parent is driving the child to school, then allow them to park as close as possible to school entrance.

Applying sunscreen

Young children will need help with applying sunscreen to all exposed areas of skin. It is recommended this is done at least twice during the school day, but the child's parents should give you the sun cream and tell you about their routine. You will need to consider where the sunscreen will be stored, who will apply it during the day, and a private place where this can be done.

As the child gets older he/she should be encouraged to apply his/her own sunscreen with supervision as needed.

Wearing UV protective clothing

- Teachers need to know where the child's UV protective clothing is at all times in case of fire/fire drill, so the child can stay protected if he/she needs to go outside.
- Remember that the child will only be able to remove his/her visor, gloves and hat when away from any source of UV light.

Planning playtime and PE

It can be challenging to balance the child's need for exercise and peer interaction, with the need to keep away from UV daylight. You might want to consider the following strategies:

- Have access to indoor space during break time, with enough space to run and play with friends.
- Have PE lessons indoors if at all possible.
- Provide a safe outdoor play space protected from daylight.
 - Provide a shaded area in the playground, remembering that if daylight is still present UV protective clothing will be needed.
 - Structure PE lessons, timetabling them for end of day or beginning of day when UV levels tend to be lower.
- Allow the child with XP to be totally covered if outdoors during PE: track bottoms long sleeve tops, gloves, hat and visor.

Going on school trips

A child with XP should be able to go on school trips if planned in advance. Discuss the trip with the child's parents and think about ways to minimise UV exposure. Coaches need to have blinds or curtains which can be closed as necessary.

Think about the time of day and the length of time the child will be outside and if any extra precautions may be needed. Remember the child will need to wear UV protective clothing and apply sunscreen regularly.

Explaining XP to other children/peer group

It is natural for other children to be curious about why the child with XP needs to be protected from UV light, especially as the child's hat and visor will be visible. A simple explanation is

normally sufficient. However please be aware of the potential for bullying and take appropriate action as required.

Taking time off school

The National XP service runs a clinic in London and children with XP are asked to attend at least yearly, and the pupil may need to take a day off. The child will also have hospital appointments locally. If any of this time off affects school performances, please tell the XP clinical nurse specialist.

Checklist

- Ensure you have gathered any necessary information about the child's individual needs from his or her parents and previous school if relevant.
- Arrange a visit from an XP clinical nurse specialist to find out more about XP, and to assess UV levels in the school
- Arrange for any environmental protective measures to be put in place, for example UV protective window film, bulb covers as required
- Assess if the pupil's timetable needs to be altered, for example, changing classrooms
- Ensure a named person is identified to help apply sun protection and be responsible for safety of child during fire drills
- Put any necessary planning in place for school trips
- Put a plan in place for travel to and from school
- Ensure you have relevant contact numbers

Useful sources of information

XP Support Group – offers advice and practical help to anyone affected by XP.
t: 01494 456 192 e: info@xpsupportgroup.org.uk w: www.xpsupportgroup.org.uk

Contact us

If you would like an XP clinical nurse specialist to visit the school to speak to staff, or if you would like advice over the telephone, please contact:

Sally Turner (children's XP nurse specialist), St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH
t: 020 7188 6339 e: sally.turner@gstt.nhs.uk

Patient Advice and Liaison Service (PALS) – To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:
t: 020 7188 8801 at St Thomas' t: 020 7188 8803 at Guy's e: pals@gstt.nhs.uk

Language support services – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.
t: 020 7188 8815 fax: 020 7188 5953