

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

This leaflet aims to:

- give teachers more information about xeroderma pigmentosum (XP)
- offer guidance on how to make the school environment safe for a child with XP
- outline the general support needed by all children with XP.

XP affects children in different ways, so to understand more about a child coming to your class, we recommend talking to their parents before they start school.

What is XP?

XP is a rare skin condition that some people are born with. In XP, the skin 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 UV light and are more likely to develop skin cancers if they do not protect themselves from the harmful effects of UV light. In some people XP can also cause problems with the nerves or brain.

XP is rare and only affects one in 250,000 people. 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 on the left 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 can attend school alongside children of their own age. However, it is important 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

It may help to have a visit from an XP clinical nurse specialist to find out more about the condition. The nurse can advise on any changes that are needed before the child starts school.

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

Planning is needed for the child to join in lessons away from possible sources of UV light. It can be helpful to walk around the building with the pupil's timetable, identifying any risks. A UV meter is helpful to measure the levels of UV 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.

For more information on how to use a UV meter, please read our leaflet, **Xeroderma pigmentosum: using an ultraviolet (UV) meter**. You can ask the XP clinical nurse specialist for a copy.

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 of low risk, as are LED bulbs.
- Compact fluorescent and fluorescent strips are more of a risk. It is best to cover these with a protective sleeve or use the type in a protective case.
- Avoid halogen bulbs.

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 may qualify for a school taxi to the school door, to limit their time outside. Ideally the taxi should have tinted windows or be protected by UV window film. If this is not possible, the child should wear full UV protective clothes.
- If the parent is driving the child to school, allowing them to park as close as possible to the school entrance will limit the child's UV exposure.

Applying sunscreen

Most young children need help applying sunscreen to all exposed areas of skin. We recommend this is done at least twice during the school day. The child's parents should give you the sun cream and tell you about their routine. Consider where the sunscreen will be stored, who will apply it during the day, and a private place to do this.

As the child gets older encourage them to apply their own sunscreen with supervision as needed. Having a mirror may make this easier.

Wearing UV protective clothing

- Make sure you 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 they need to go outside.
- Remember that the child will only be able to remove their 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. 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. Be aware they may get hot before the other children do.

Going on school trips

A child with XP can 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. 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. 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 or 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

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

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:

e: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

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