

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

This leaflet will give teachers more information about XP, offer guidance on how to make the school environment safe for a child with XP, and outline the general support needed by all children with XP. It 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 ultraviolet radiation (UVR). 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 UVR (see page 2)
- need to wear visor, gloves, long sleeves and hat when near any unprotected source of UVR (see photo on the left and page 3)
- need to apply sun protection factor (SPF) 50+ sunblock regularly (see page 3).

A young boy with XP wearing a UV protective visor.

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

With the right support, children with XP can attend school alongside other 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 an educational health care plan – you can find out more about this at www.gov.uk/children-with-special-educational-needs

Arranging a visit from the XP clinical nurse specialist

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

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

Planning is needed for the child to join in lessons, away from possible sources of UVR. 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 UVR, and the XP clinical nurse specialist can discuss this with you. You may also want to consider changing classrooms or timetables to avoid potential UVR 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 CNS for a copy.

High risk: windows and door panels

- UVR can travel through glass.
- Glass may need to be covered with UV filter film that will not affect the visible light levels in a room. Various companies offer this protective film, but the XP CNS can advise you if you need help. Some modern windows incorporate a UV filter when they are made.
- 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 UVR.
- Consider using blinds as a substitute for UV filter 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 UVR.
- Incandescent bulbs are of low risk, as are LED bulbs.
- Compact fluorescent and fluorescent strips are a higher 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, tablets, 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 UVR exposure.

Applying sunblock

Most young children need help applying sunblock 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 block and tell you about their routine. Consider where the sunscreen will be stored, who will apply it during the day, and that they will need a private place to do this.

As the child gets older, encourage them to apply their own sunblock 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 UVR.

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 UVR. 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 still be needed.
 - Structure PE lessons, timetabling them for the end or beginning of the day when UVR levels tend to be lower.
- Allow the child to be totally covered if outdoors during PE: tracksuit bottoms, long sleeve tops, gloves, hat and visor. Be aware that they may get hot, and also thirsty 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 UVR 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 UVR, 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 if 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 their performance at school (their behaviour or missing too many lessons), please tell the XP clinical nurse specialist.

Checklist

- Ensure you have gathered any necessary information about the child's individual needs from their parents, and previous school if relevant.
- Arrange a visit from an XP CNS to find out more about XP, and to assess UVR levels in the school.
- Arrange for any environmental protective measures to be put in place, for example UV protective window film or bulb covers if 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 the safety of the child during fire drills, or emergency evacuations.
- 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

Teddington Trust – offers advice and practical help to anyone affected by XP.

t: 01233 645360 **e:** support@teddingtontrust.com **w:** www.teddingtontrust.com

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, the 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

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111

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