

# Xeroderma pigmentosum: using an ultraviolet (UV) meter

The leaflet aims to explain:

- what is ultraviolet radiation (UVR)
- what is a UV meter
- information about using a UV meter if you have Xeroderma pigmentosum
- advantages of using a UV meter.

If you have any questions or concerns after reading this leaflet, please speak to a doctor or nurse caring for you.

## What is ultraviolet radiation (UVR)

Daylight contains light you can see as well UVR that you cannot see. UVR is a part of the light spectrum that is not visible to the eye. It can cause cell damage in the skin and eyes. It is divided into 3 bands: UVA, UVB and UVC.

- UVA is mainly responsible for skin ageing and is now thought to contribute to some skin cancers.
- UVB is responsible for sunburn and skin cancers. UVB is considered the most harmful type of ultraviolet radiation to those with XP.
- UVC from the sun is mostly absorbed by the ozone layer so there are minimal chances of it causing damage. However there are artificial sources of UVC, which should be avoided (see overleaf).

UVR can vary depending on the following:

- Time of day – the higher the sun in the sky, the higher the UVR
- Time of year – highest during summer months
- Geographic location – the sun's rays are strongest at the equator
- Altitude – UVR increases with altitude, less atmosphere to absorb the damaging rays
- Clouds – heavy cloud cover usually reduces UVR but does not completely stop it
- Environment – UVR rays are reflected on surfaces e.g. snow, water, sand, concrete, and glass.

## Sources of UVR (Artificial and non-artificial)

UVR energy is produced by the sun but can also be produced artificially, for example in light bulbs.

- Any form of daylight (any time the sun is above the horizon even if it is an overcast day)
- Some light bulbs especially halogen and fluorescent
- Mercury lamps
- Germicidal lamps
- Tanning or sun beds.

UVR can also travel through windows, including the windows of cars.

For more details please refer to the information leaflet **Xeroderma pigmentosum** - please ask a member of staff for a copy.

## Why is UVR more harmful to people with XP?

UVR can cause cell damage in the skin of anyone exposed to it. Most of the time a person without XP can mend this damage. However those with XP do not have the ability to mend cell damage due to a fault in the repair pathway the body uses to correct this damage. They therefore run a high risk of any damage turning into skin cancers, along with causing dense freckling and often severe and prolonged sunburn to all UVR exposed areas of skin. Those with XP are at most harm from UVB and UVA.

## What is a UV meter?

A UV meter is a hand held, battery operated device that can measure UVR in your environment. It measures UVR coming through windows and light sources such as light bulbs.

## Information about using a UV meter if you have XP

We do not know exactly what level of UVR exposure will result in a particular amount of skin damage. Individuals vary in their own skin's ability to repair UVR damage, whether it is caused by a one-off high exposure or a build-up of continual low exposure. There is no published 'safe level' of UVR.

A UV meter will only give an indication of the UVR levels in a particular place at a particular time. A zero reading does not mean a place is completely UVR safe but indicates a very low UVR reading (less than 1uW/cm<sup>2</sup>).

If your meter has a reading of **one or above**, we advise that you take precautions to protect all your exposed areas of skin from UVR, by using sun screens, a face visor or UV protective glasses and protective clothing. For measures to reduce risk from these sources please refer to the leaflet **Xeroderma pigmentosum**.

If your meter stops working or you believe it to be faulty please contact the XP clinical nurse specialists (contact number on the next page).

UV meters are not medical devices so need be used along with good judgement.

## **Advantages of using a UV meter**

Although we cannot see UVR, it can be measured using a UV meter. Various UV meters are available on the market. It is important to know exactly which wavelengths they are designed to measure to be able to assess if they are effective for the task they will be used for. We can recommend meters that have been tested by our medical physics department.

A meter that measures UVA and UVB wavelengths can help inform a person with XP of their exposure risk in their everyday lives, enabling them to take action to reduce the risk. We recommend trying the UV meter in different lighting conditions both indoors and outdoors to get to know what is a high and low reading. The meter reading can warn you if the UVR levels are high and confirm when levels are low.

It will give a visible reading to the levels of UVR that you cannot see. This can be helpful, especially in an unfamiliar area that does not have UVR protection in place.

## **How do I get a UV meter?**

Contact the XP clinical nurse specialists (contact details on next page) who can advise on meters that have been tested and are considered suitable for people with XP.

## **Useful sources of information**

**Guy's and St Thomas' website** – provides useful information on our XP service, including our patient leaflets **w:** [www.gstt.nhs.uk/xp](http://www.gstt.nhs.uk/xp)

**XP Support Group** - offers advice and practical help to anyone affected by XP  
**t:** 01494 456 192    **e:** [info@xpsupportgroup.org.uk](mailto:info@xpsupportgroup.org.uk)    **w:** [www.xpsupportgroup.org.uk](http://www.xpsupportgroup.org.uk)

## Contact us

If you have any questions or concerns about XP, please contact the XP nurse specialists on 020 7188 6339 or 020 7188 6351 (Monday to Friday, 9am to 5pm). Out of hours, please leave a message on the answer phone with your contact details.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

**Meter checks** – For advice on UV meters and for meter checks please contact the medical physics department

**t:** 020 7188 3811 **e:** [andrew.coleman@gstt.nhs.uk](mailto:andrew.coleman@gstt.nhs.uk) or [fiammetta.fedele@gstt.nhs.uk](mailto:fiammetta.fedele@gstt.nhs.uk)

### 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](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@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:

**t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto: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

### NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

### Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

**t:** 0800 731 0319 **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk) **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

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