

ORAL PUVA PHOTOTHERAPY

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about oral PUVA (psoralen + UVA) phototherapy for your skin condition. This leaflet explains this treatment in detail, including its risks, benefits and alternatives. If you have any questions or concerns, please speak to the doctor or nurse caring for you.

WHAT IS PHOTOTHERAPY?

Natural sunlight has been known to be beneficial in certain skin disorders for thousands of years. Phototherapy is a specialised treatment, delivered by the Phototherapy Unit at your hospital. It is carefully regulated to ensure patient safety and has proven to be a very effective treatment for many different skin diseases.

The ultraviolet radiation (UVR) produced by the sun is used in phototherapy. Although it cannot be seen, UV radiation is an important part of sunlight and is divided into ultraviolet A (UVA) and ultraviolet B (UVB) wavelengths. UVA rays go deeper into the skin than other types of UVR and can cause the skin to tan. UVB rays do not penetrate as deeply but can cause the skin to burn. In phototherapy we use carefully calculated doses of UV light to minimise this risk.

WHAT IS ORAL PUVA?

Oral PUVA therapy is a treatment in which a medication called psoralen (P) is taken by mouth usually 2 hours before exposure of the skin to ultraviolet A (UVA) wavelengths of light. The number of tablets you will take depends on your height and weight and you will be given this medication from the hospital pharmacy.

The psoralen reacts in the skin with the UVA to cause effects that help improve or clear a variety of skin conditions. The tablets also make you more sensitive to UVA in sunlight (the rays

that get through cloud and window glass) on the days of your treatment.

ARE THERE ANY OTHER TYPES OF PHOTOTHERAPY?

Other phototherapy treatments include:

- **Narrowband UVB (NB-UVB):** Uses a small part of the UVB light spectrum to treat skin conditions.
- **Topical PUVA:** Psoralen is applied directly to the skin before giving UVA.
- **UVA1:** This type of UVA penetrates to the deepest layers of the skin.

The choice of phototherapy recommended depends upon your skin condition, and on discussions that you have with your doctor about the treatment that would work best for you and be most suitable for you.

WHAT SKIN CONDITIONS ARE TREATED WITH ORAL PUVA AND WHY AM I HAVING THIS TREATMENT?

You and your healthcare professional will have talked about treatment options for your skin condition and decided that this treatment is the most suitable.

This treatment is usually recommended if ointments and creams have not helped sufficiently, but usually before trying tablet medication. Oral PUVA therapy has been found to be a particularly useful treatment for many skin conditions including [psoriasis](#), plaque stage [mycosis fungoides](#), pityriasis rubra pilaris and generalised or [hand](#) and foot eczema. It is occasionally used in other conditions if UVB treatment has not worked, for example in [psoriasis](#), [eczema](#) or [vitiligo](#), as PUVA may be more effective.

THE TREATMENT PROCESS

What can I expect on my first treatment?

On your first visit to the phototherapy unit, you will have a pre-treatment nursing assessment. Before starting the course of PUVA treatment, you will usually need to undergo a test called MPD (minimal phototoxic dose) testing. MPD testing involves shining a few small doses of UVA light onto small areas of skin (for example, the arm), 2 hours after you have taken a standard dose of psoralen tablet. The entire process takes around 30 minutes, and the redness response will be checked in 3-4 days to determine your starting dose of light for the UVA machine.

What happens during treatment?

You should take the prescribed number of tablets 2 or 3 hours (depending on the type of psoralen prescribed) before attending for treatment and the test dose. The tablets should be taken with a light meal or snack—**avoid taking them on an empty stomach or with a full meal, as this may change their effectiveness.**

Before each session, the phototherapy nurse will examine your skin and ask you some questions. You will be given protective goggles for your eyes, which must be worn at all times during treatment. Men must either wear dark underwear or cover their genitalia whilst in the booth.

You will be guided on how to stand in the machine to ensure your skin is exposed evenly each time.

Initially, you will be in the UVA machine for a few minutes, but it can eventually be around half an hour. The amount of UVA you receive will be closely monitored and will be increased every 1-2 treatments if you have tolerated the previous treatment. The light in the machine is quite bright and you may feel warm if you stay in the booth for a long time. Please let the nursing staff know if you feel uncomfortable or unwell.

How long do treatments last?

This depends on your skin condition and varies from person to person. Treatments are generally given twice a week with at least 3 days between treatments (either Monday/Thursday or Tuesday/Friday) for 10–20 weeks. Individual

PUVA treatments last up to a few minutes initially and subsequent visits would last longer if you can tolerate them. Each visit may take up to half an hour.

Important points to remember before and during your treatment

- You should avoid alcohol before your treatment.
- You need to commit to attending the phototherapy department twice per week. Attending regularly helps to achieve better results from your treatment.
- Psoralen makes your skin more sensitive to sunlight so you should minimise sun exposure to reduce the risk of sunburn:
 - On days you have taken psoralen tablets, wear long sleeved clothes and a hat when outdoors, even on cloudy days.
 - After treatment, use at least an SPF 50 (sun protection factor 50) sunscreen with a UVA 5-star rating and re-apply it regularly (*do not apply before treatment as this may stop the PUVA from working*).
 - Do not sunbathe or use a sunbed during the whole course of your treatment.
- Newly exposed areas of skin during your treatment can burn. Let your phototherapy team know if you get a haircut or if any new areas of skin become exposed.
- Be consistent with the way you wear clothing or jewellery during treatment. This is because the dose of UV light increases with each session, and it may be too strong for skin that has not been gradually introduced to the therapy.
- Inform staff of any medication changes, including over-the-counter drugs or creams, as some can affect UVA sensitivity, including supplements.
- Men must wear protective genital coverings during treatment.

On the day of your treatment

- Do not wear perfumes, deodorants, aftershave lotions or other cosmetic



products before your treatment. Some of these contain substances which make your skin more sensitive to light. This can cause patchy discolouration of the skin that can take some months to fade. You can use them after each treatment.

- On treatment days please do not apply any creams or ointments to your skin before you go in the machine. However, a non-SPF, water-based **emollient** can be applied 2 hours before treatment, as this may help your skin to absorb the ultraviolet light, especially if your skin is scaly. Please ask your nursing team for more information on this.
- Do not use oily creams as these could cause burning or prevent the UVA from being absorbed.

Special requirements for PUVA treatments

Psoralen tablets make both the skin and the eyes sensitive to light for 12-24 hours.

You must wear protective glasses for at least 12 hours after taking psoralen tablets. This includes both outdoors in daylight and indoors near windows. Wearing protective glasses will reduce the risk of eye inflammation and long-term cataracts (clouding of the lens of the eye).

Children and those at higher risk of cataracts are advised to wear sunglasses when in daylight for 24 hours. The nurses will advise you on suitable eyewear and will test your glasses to check that they offer 100% UV protection. You must also wear the protective goggles and face shield provided during treatment unless the doctor tells you not to.

You need to take extra care throughout the course of PUVA treatment to protect your skin from sunlight.

UVA light can penetrate through glass and cloud, so care needs to be taken both indoors and outdoors during daylight hours.

WHAT ARE THE RISKS WITH ORAL PUVA PHOTOTHERAPY?

Psoralen **will** make you more sensitive to UVA in sunlight (the rays that get through cloud and window glass) during the treatment. It is important to avoid sunlight or protect your skin

anytime you are outside or near a sunny window after taking your psoralen tablets until end of daylight on that day.

Your doctor or nurse will discuss the possible complications of this treatment with you in more detail, but you need to be aware of the following:

Side effects that could happen during your course:

- **Mild sunburn:** It is likely that you will get a mild sunburn reaction at least once during your course, and this can take 2-3 days to appear and could last for more than a week.
- If you get a severe sunburn-like reaction, contact your phototherapy unit, or contacts provided for advice. If there is any delay in getting further advice, you can apply a steroid ointment if you have one at home, along with moisturisers. You can also take painkillers such as paracetamol or ibuprofen for any pain. More information on dealing with sunburn can be found on the NHS website here: www.nhs.uk/conditions/sunburn/
- **Spotty itchy rash:** We know that about 1 out of 10 people develop spotty itchy rash during their course of treatment. This is called **polymorphic light eruption** or prickly heat. If you already know that sunlight causes this reaction on your skin please tell the nurse or doctor before you start treatment. If this happens during your course of treatment, please tell the nurse as soon as possible.
- **Tanning:** Depending on your natural skin colour, if your skin goes brown easily in sunlight, you may develop a dark tan.
- **Dry itchy skin:** This is common, and we recommend using a regular moisturiser/emollient between treatments to reduce this. However, avoid using these for at least 2 hours before your treatment, but they can be applied immediately afterwards.
- **Feeling sick:** If taking 8-methoxypsoralen (8-MOP) you might feel sick after taking the tablets- please tell the nurse if this happens to you. This can be helped by taking an anti-sickness tablet before the psoralen



and by making sure that any further treatments are not taken on an empty stomach.

- **Caffeine sensitivity:** Psoralen tablets may increase the levels of caffeine from coffee, tea and cola drinks in your blood. If you feel "jittery" on your PUVA days try reducing the number of caffeinated drinks you drink.
- **Cold sores:** These may affect one in thirty people who have PUVA to the facial area. Tell your nurse if you notice early signs of tingling or a painful bump developing on your lips. If you have a history of cold sores they will apply sunblock to lips before each treatment.
- **PUVA pain:** Rarely, you may develop a prickling, tingling, crawling sensation on your skin without there being anything to see. You must report this to your PUVA team immediately. If this PUVA pain occurs then it may persist for weeks to months and will likely recur if PUVA is used again, so you would be advised to stop PUVA and use treatments that are sometimes used for nerve-type pain.
- **Worsening of the condition being treated:** This may occur instead of improvement and your doctor will advise you of the risk of this happening.

If you develop any of these side effects or any other symptoms that you think may be PUVA-related, please talk to the nursing staff.

Always inform a member of staff if you are unwell or unable to attend treatment.

WHAT ARE THE RISKS ASSOCIATED WITH MULTIPLE COURSES OF PUVA?

- **Skin cancer:** People with a lot of sunlight exposure have an increased risk of skin cancer. In the UK, approximately one in every 4-5 of us will develop skin cancer. This risk is higher with PUVA than with sunlight and depends on how many whole-body PUVA treatments you have had. If you have received more than 150-200 PUVA treatments, you may be asked to attend your local clinic for regular skin cancer screenings. It is unlikely that you would be advised to continue PUVA treatments

beyond 150-200 treatments and in this case, other treatment options will probably be discussed.

- **Skin-aging:** If you undergo many treatments, you may develop skin changes similar to aging or those caused by smoking, such as wrinkling and skin discolouration. Increased freckling can also occur.

WHERE CAN I GET MORE INFORMATION ABOUT PHOTOTHERAPY?

The process of phototherapy can raise many questions, and sometimes also thoughts and feelings about your skin condition. The list below contains information about some of the Patient Support groups that provide support during, and information about, the process of phototherapy.

It is important to report suspected side effects of medicines and treatments. The Medicines and Healthcare products Regulatory Agency (MHRA) manages the Yellow Card scheme. This scheme collects information and safety concerns about medicines and medical devices. Anyone can report these side effects or concerns by using:

- the Yellow Card website
www.mhra.gov.uk/yellowcard or
- the Yellow Card app

Patient support groups providing information:

Psoriasis Association:

www.psoriasis-association.org.uk

Psoriasis and Psoriatic Arthritis Alliance

www.papaa.org

National Eczema Society:

www.eczema.org

Vitiligo Support Group:

www.vitiligosupport.uk

Vitiligo Society

www.vitigosociety.org.uk

Cutaneous Lymphoma Foundation:



www.clfoundation.org

Lymphoma Action

www.lymphoma-action.org.uk/types-lymphoma-skin-lymphoma/skin-cutaneous-t-cell-lymphoma

Other relevant resources:

Skin cancer symptoms and treatments:

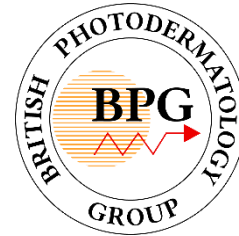
www.skinhealthinfo.org.uk/symptoms-treatments/skin-cancer/

Jargon Buster:

www.skinhealthinfo.org.uk/support-resources/jargon-buster/

In addition, the nursing staff of your Phototherapy unit are more than happy to answer questions about your course of treatment or anything that arises from the treatment.

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.



This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists and the British Photodermatology Group: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

BRITISH ASSOCIATION OF DERMATOLOGISTS

PATIENT INFORMATION LEAFLET

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