

Patient information

Treating skin conditions to the hands and/or feet with topical PUVA therapy

You have been referred for a course of PUVA therapy. This leaflet explains about the treatment, including potential risks and benefits. If you have any questions or concerns, please ask the dermatology nurse or doctor.

What is topical PUVA?

Topical PUVA is a treatment which uses the combination of Ultraviolet light (UVA) and a chemical originally derived from plants called Psoralens. The Psoralens is applied to areas of skin to be treated in the form of a gel.

What is Ultraviolet A light (UVA)?

Ultraviolet light rays are produced by the sun. They are not visible and are grouped into different wavelengths: UVA, UVB and UVC.

What does topical PUVA treatment involve?

Topical PUVA is used to treat Psoriasis, Eczema and other skin conditions affecting the hands and/or feet.

What will happen when the Dermatology doctor has referred for treatment?

The Lead Phototherapy Consultant Dermatologist will review all referrals to check that your condition is suitable for treatment. You will be contacted regarding your preferred appointment time and a note will be made of any planned holidays. The length of treatment course required to treat your condition will be discussed. Your name will be added to the waiting list and you will be contacted when a course of appointments become available. Treatments are usually administered twice weekly for a period of ten weeks.

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It is important that all treatments are attended to achieve a good response to treatment. If the first appointment is missed or a total of two appointments are missed during the course, the treatment course will be discontinued. Please be prompt to all appointments.

What are the alternatives to treatment?

A range of cream and ointment-based treatments are available which can be used alone or to maximize the effectiveness of the light treatment. Tablet or injection treatments may be appropriate for some individuals. Your doctor should have discussed suitable options with you. Please ask the doctor or nurse if you have any questions.

What does the treatment involve?

Treatments are administered by specially trained nurses in the Phototherapy treatment rooms, located in the Pain Clinic Outpatients department (OPD E) at West Suffolk Hospital. On arrival you will be asked to be seated in a small waiting area outside the treatment rooms. You will be asked to complete a pre-treatment questionnaire and the nurse will examine the skin before each treatment to assess how well your skin is responding.

A thin layer of Psoralens gel will be applied by the Phototherapy nurse to the localized areas of skin requiring treatment. This will be left in place for a minimum of 30 minutes prior to the administration of the light treatment to increase sensitivity of the skin to the light. The Phototherapy nurse will obtain this gel from the hospital Pharmacy.

Once the Psoralens gel has been applied, you should avoid touching and spreading the gel to other skin areas.

Psoralens gel is an 'unlicensed' drug. This means that the product does not have a full product license in the UK. Medicines are often used when they do not have a product license and there can be many reasons for this. Products such as Psoralens gel are used across the UK only within specialist centres. With limited alternative products available, finding enough patients for large clinical trials is likely to be difficult and expensive. The referring clinician and the Phototherapy nurse will consider the medical evidence available in relation to your condition and the Pharmacy will have ensured that the product has been manufactured to a good standard and is of acceptable quality. Psoralens gel is commonly used in Phototherapy departments for the purpose of administering light treatment however please discuss any concerns with the Phototherapy staff.

You will be asked to be seated at the hand and foot PUVA treatment machine and will be assisted by the nurse with positioning of the skin areas to be treated. Protective goggles will be provided and towels will be placed over the light treatment canopies to minimize stray light.

The nurse will ask for confirmation of name and date of birth, the machine dose set and a calculated dose of light treatment will be given.

The Phototherapy nurse will ask you to wash off the Psoralens gel before leaving the clinic; an emollient wash is usually available in clinic this purpose. Assistance will be provided if required.

At the first session, there will be an opportunity to discuss the potential benefits and side effects of light therapy with the nurse. You will be asked to sign a consent form to confirm you agree to treatment. You will be required to provide a list of all current medicines taken (both those prescribed by your GP and also ones purchased at the chemist). It is important that you bring a list with you to the initial appointment.

You may be asked whether you would be agreeable to have photographs taken of affected skin areas by the Medical Photographer for record/teaching purposes.

Patient responsibilities

You must inform the nurse if you have experienced the following:

- If you have lots of moles
- If you have had skin cancer
- If you have noticed an unusual skin lesion
- If you have noticed sensitivity to the sunshine or previous light therapy
- If you have had radiotherapy
- If you have had an organ transplant
- If you have any type of cardiac implant or Pacemaker (we do not recommend light treatment if you have a Pacemaker)
- If you have any other type of implant (including metalwork)
- If you think you may be pregnant or if you are breastfeeding (PUVA treatment is not advised during pregnancy or whilst breast feeding)
- If you suffer from Epilepsy

Fragranced products such as perfumes, aftershave lotion, deodorants and greasy ointments must not be present on the skin when attending for

treatment: These can increase the potential for developing a burn and can cause a discolouration to the skin. The nurse must be informed of any change in cream or ointments used and any change in medication before each treatment.

Facial make up and cosmetic products should not be present on skin areas being treated: Make up can be worn if the face shield is being used.

It is important to moisturise the skin *before* light treatment using a cream (water based) product. Greasy moisturisers such as white soft paraffin, Vaseline, 50/50 liquid/soft paraffin, Epaderm ointment and Hydromol and other ointments should not be applied on the morning before treatment. Use of an appropriate cream based moisturiser is advised pre-treatment.

It is important to moisturise the skin *after and between* treatments: Moisturising the skin can be important in maximising the effectiveness of the light therapy. A moisturiser should be used as advised by the Dermatology doctor/nurse.

Sun exposure must be avoided between treatments: It is important to cover the treated areas of skin, particularly on sunny days. Long sleeved clothes and a hat may be necessary. Use of a sunscreen with a factor of at least 30 to protect against UVA and UVB rays is advised. Sunbathing and use of sunbeds must be avoided during a course of light treatment. If your skin shows sign of sunburn, treatments will be refused.

It is important that the nurse is informed of any changes to your medicines, cream/ointment treatments or general health: Certain medicines and cream/ointment treatments can make the skin more sensitive to light treatment. It is important that you let the nurse know if you feel too unwell to have treatment.

Jewellery: Jewellery (including piercings) must **not** be worn during treatment unless impossible to remove. Jewellery should be left at home and **not** be brought into the department. West Suffolk NHS Foundation Trust are not able to take responsibility for any personal belongings (including jewellery).

Attendance: Treatments will be administered twice weekly. You are requested to be prompt to appointments otherwise it may not be possible to receive your treatment. We try to keep to your appointment time but occasionally there are unavoidable delays. Please let the nurse know if you have concerns.

Parking: Please ensure that you bring in your appointment letter as this will be required to enable you to park without a charge. You will be asked to take your appointment letter into the parking office near the West Suffolk Hospital main entrance after each appointment. **Please allow 60 minutes for the initial**

appointment and 60 minutes for further treatments.

Side effects: The Phototherapy nurse should be informed of any problems experienced during or after treatments.

Possible side effects from treatment

- The skin may become itchy and dry.
- Your skin condition may temporarily seem worse.
- It is usual to feel warm during treatment but treatments are short and generally well tolerated.
- Freckles can temporarily become darker in colour.
- Some skin tanning is likely. Your skin may burn as with exposure to any form of sunlight. We try to avoid this but slight redness of the skin is likely. If mild skin redness develops, please let the nurse know when you attend for your next treatment. If you think you have signs of severe sunburn (sore, deep red or blistered skin) you must seek urgent medical advice from your GP (this may be the 'out of hours' GP service or Accident & Emergency department).
- It is advised to wear protective goggles as provided for treatment. It is thought that unprotected exposure to ultraviolet light may increase the risk of developing eye cataracts in the future.

What will happen when the treatment course is completed?

An appointment will be made to be seen in the dermatology clinic. You should continue to apply any cream and ointment-based treatments as advised. We would be grateful if you could complete a patient satisfaction questionnaire, as comments will be used to make changes to improve the clinic.

A possible increased risk of skin cancer can be associated with over exposure to ultraviolet radiation.

Cancer Research UK advise that the most important thing you can do is to protect your skin from sunburn. You can use the shade, clothing and sunscreen (at least factor 30 applied generously and regularly) to protect your skin. It is advisable to get into a habit of observing your own skin and to ask your GP to check your skin if you notice any changes or abnormal areas.

Further information regarding sun protection and skin changes can be accessed on the Cancer Research UK and British Association of Dermatologists websites.

Who can I contact with any queries about my treatment?

During the Phototherapy clinic hours (1.30 pm to 5.00 pm Monday, Wednesday and Friday afternoons): please phone 01284 712576.

Outside of the above clinic hours: please phone the Dermatology nurses office on 01284 713575.

Information and support

Support groups (such as the following) may be useful:

- British Association of Dermatologists <u>www.bad.org.uk</u>
- Cancer Research UK <u>www.sunsmart.org.uk</u>
- DermNet NZ <u>www.dermnet.nz.org</u>
- Lupus UK <u>www.lupus.org.uk</u>
- National Eczema Society www.eczema.org
- Psoriasis Association <u>www.psoriasis-association.org.uk</u>
- Vitiligo Society <u>www.vitiligosociety.org.uk</u>

If you would like any information regarding access to the West Suffolk Hospital and its facilities please visit the hospital website www.wsh.nhs.uk and click on the link, or visit the disabledgo website:

http://www.disabledgo.com/organisations/west-suffolk-nhs-foundation-trust/main

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