

ORAL PUVA PHOTOTHERAPY TREATMENT

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 part of the radiation produced by the sun (UVR) is used in phototherapy. Although it can't 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 PUVA?

Oral PUVA therapy is a treatment in which a medication called psoralen (P) is taken by mouth 2-3 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?

The other phototherapy treatments are Narrowband UVB (NB-UVB), in which a small part of the UVB light spectrum is used to treat the skin condition; topical PUVA, where psoralen is applied directly to the skin and UVA1. The choice of phototherapy treatment depends upon your skin condition, and on discussions that you have with your doctor about the treatment that would work best for you.

What skin conditions are treated with oral PUVA and why am I having this treatment?

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

It is often recommended if you have tried ointments and creams without success, but before trying other tablet medication. Oral PUVA therapy has been found to be a particularly useful treatment for many skin conditions including psoriasis, plaque stage mycosis fungoides and hand and foot eczema. It is occasionally used in other conditions if UVB treatment has failed, for example eczema or vitiligo, as PUVA is a more potent form of treatment than UVB.

The Treatment Process: What can I expect on my first treatment?

On your first visit to the unit you will have a pre-treatment nursing assessment. Before you begin the light treatment you will usually need to attend for a series of small test doses, called MPD (minimal phototoxic dose) testing. A number of doses of ultraviolet A will be shone on small squares on your back, 2 hours after you have taken a standard dose of psoralen tablet. This takes around 30 minutes and the result will be read 4 days later. This result will help your nursing team to decide your starting dose in the machine. It also makes sure that the dose of psoralen given is correct for you so that it leads to enough psoralen in your skin.

Your first treatment in the UVA machine will only happen after your MPD test is completed.

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. They should not be taken on an empty stomach but with a light meal or snack. However, do not take them with a full meal as this can prevent them from being effective.

The nurse will examine your skin on each visit and ask you some questions before you enter the machine. They will give you goggles to protect your eyes, which you must wear at all times during your treatment. Men will also be given genital protection. You will be shown how to stand in the machine in the correct position to make sure that all your skin is exposed evenly each time.

Initially you will be in the UVA machine a few minutes, but it can eventually be as long as an hour. The amount of UVA you receive will be closely monitored and will be increased with each treatment as long as you have tolerated the previous treatment. The machine is quite bright and you may feel warm if you need to stay in the booth for a long time. Please let the nursing staff know you feel uncomfortable or unwell.

How long do treatments last?

This depends on your skin condition and varies from person to person. We generally give treatments twice a week (either Monday/Thursday or Tuesday/Friday) for 10–20 weeks. Individual treatments initially last up to a few minutes with an increased duration with each subsequent visit if tolerated. The total visit may take up to half an hour. The total number of treatments will depend on response to treatment and your specific skin condition.

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.
- Reduce exposure to the sun's rays to minimise the risk of sunburn: On days you have taken tablets, cover up with long sleeved clothes, particularly on sunny days. You may also need to wear a hat. Use a sunscreen with a sun protection factor (SPF) of a least 50 with a UVA seal of protection that protects against UVA and UVB rays and re-apply it regularly. Please do not sunbathe or use a sunbed during the whole course of your treatment.
- Let your phototherapy team know if you have a haircut or, for any other reason, any areas of skin become newly exposed during the course of treatment. If you wear clothing during treatment it is important that you wear the same clothing or the exact same style for every treatment of the course.

- Before you start PUVA treatment the doctor and nurse will check the medicines that you are taking. If any medications you are taking (including anything you are taking over-the-counter) are changed during PUVA treatment, please let the nursing staff know before they start your next treatment. This is because some tablets can affect the way your skin reacts to UVA.
- Male genital protection must be worn when in the machine.

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 and take some months to fade. You can use them after each treatment.
- For the same reason please let your phototherapy team know if you have started any new medications or creams whilst having treatment as some can make your skin more sensitive to light.
- On treatment days please do not apply any creams or ointments to your skin before you go in the machine apart from an appropriate moisturiser. You may wish to moisturise with a water-based moisturiser beforehand as this helps your skin to absorb the ultraviolet light. 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 during daylight and indoor light exposure for 24 hours after you take your tablets (not while sleeping or driving at night) to avoid increasing the risk of cataracts (clouding of the lens of the eye). 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 the skin from light. UVA light can penetrate through glass and cloud, so care needs to be taken both indoors and out during daylight hours.

What are the risks with PUVA phototherapy?

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:

Effects that could happen during your course:

- It is likely that you will get a mild sunburn reaction at least once during your course. If you get any severe sunburn-like reactions then you should contact the phototherapy unit and speak to one of the phototherapy nurses. If there is any delay in getting further advice you can apply steroid ointment, if you have this, as well as well as using water-based moisturisers and taking painkillers such as paracetamol or ibuprofen for any pain
- More information on dealing with sunburn can be found on the NHS website here: <u>https://www.nhs.uk/conditions/sunburn/</u>
- You may get a spotty, itchy rash during your course (about one out of ten people do).
- Depending on your natural skin colour, if your skin goes brown easily in sunlight, you may develop a dark tan.
- Your skin may become dry and itchy.
- If taking 8-methoxypsoralen (8-MOP) you might feel sick after taking the tablets. This can be helped by switching you over to a different tablet called 5-methoxypsoralen (5-MOP).
- 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 amount 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.
- Deterioration of the disease 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 who have a lot of sunlight exposure have an increased risk of cancer. In the UK approximately one out of ten of us will develop skin

cancer. This risk is higher with PUVA than with sunlight and is related to the amount of overall whole-body PUVA treatments you have. It is usual practice to be asked to attend your local clinic for a specific skin cancer review once you have received more than 200 PUVA treatments.

• Photo-aging:

It is also possible if you need many treatments that you may develop sunlight-induced skin changes with wrinkling and skin discolouration, similar to that of the ageing process or produced by cigarette smoking.

Where can I get more information?

The process of phototherapy can generate lots of 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.

Psoriasis: www.psoriasis-association.org.uk Eczema: www.eczema.org www.nottinghameczema.org.uk Vitiligo: www.vitiligosupport.org.uk www.vitiligosociety.org.uk Cutaneous Lymphoma: https://www.clfoundation.org https://lymphoma-action.org.uk/types-lymphoma-skin-lymphoma/skincutaneous-t-cell-lymphoma

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.

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: 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 PRODUCED MARCH 2020 REVIEW DATE MARCH 2023