

# Oral Psoralen Ultraviolet A Radiation (PUVA) photochemotherapy treatment for your skin condition

Dermatology

Patient information

## What is this information about?

This information is about oral psoralen ultraviolet A radiation (PUVA) treatment for your skin condition. It explains:

- What PUVA treatment is.
- What PUVA treatment involves.
- The benefits of PUVA treatment.
- Other therapies that you may be able to have if you choose not to have PUVA therapy.
- The consent process.
- What you should, and should not, do on the days of your treatment.
- What happens when you are having your PUVA sessions.
- The side effects you could get from PUVA treatment and how to get help for them if you need it.
- How you should look after your skin when you are on a course of PUVA treatment.
- Who you can contact for further information or support.

## Why have I been given this information?

You have been given this information because your dermatology doctor or Dermatology Specialist Nurse thinks that PUVA would be a good treatment for your skin condition. They have sent (referred) you to the Phototherapy Unit (unit that specializes in treating skin conditions with light therapy) at Southlands Hospital for treatment.

Reading this information will help you to know what to expect from your treatment. Following the advice in it will help to make sure that your treatment works as well as possible and is as safe as possible. It will also help to keep you comfortable during the period you are having treatment.

If you have any questions or concerns after you have read this information, please speak to the doctor or nurse caring for you.

## What is PUVA?

Ultraviolet (UV) rays are produced by the sun. It has been known for thousands of years that natural sunlight can help to treat some skin disorders.

They cannot be seen by the human eye, but UV rays are an important part of sunlight. Two sorts of UV light reach us from the sun.

- **UVA.** These rays can enter our skin. They cause it to darken or tan.
- **UVB.** These rays are mostly absorbed the top layer of our skin (the epidermis). They cause sunburn.

PUVA uses both a medicine called psoralen (the 'P' in PUVA) and long-wave ultraviolet light radiation to treat you. This is why the treatment is called PUVA. It is also known as photochemotherapy.

Psoralen is a medicine made from plants that makes your skin more sensitive to light and so helps the UVA light therapy to work better.

### Be aware,

PUVA is often a good treatment for people with skin problems but may not be right for you. There may be many reasons for this including for example, if you have very fair skin or if your condition gets worse in the sunlight.

## What does PUVA treatment involve?

The treatment is given in the phototherapy room by specialist trained nurses.

- You will take the psoralen medicine by mouth (orally) two hours before you come to the Phototherapy Unit. It takes two hours for enough of the medicine to reach your skin.
- You will need to undress and stand in a phototherapy cabinet. The cabinet contains fluorescent tubes that produce UVA rays. Each machine is screened off to make sure your treatment is given in private. You will be the only patient in the room.
- If we only need to treat your hands and feet you do not have to go into a cabinet. You will sit behind a curtain at a small light machine.
- The cabinet will be turned on and you will be given the dose of UVA light that we have worked out is right for you.
- This is repeated twice a week, on Monday and Thursday afternoons at a time we will give you. Your slot will be sometime between 2pm and 4pm. You will need to come for around 12 weeks and have about 24 sessions.

Your skin may feel warm during treatment, but it will not hurt.

## How might PUVA treatment help me?

PUVA should help to improve your skin condition. We may suggest you try it if you have already tried steroid ointment and cream, but these have not made your condition much better. Sometimes we use PUVA treatment alongside other treatments. This could include treatments that you have already tried. This is more usual towards the start of your course of PUVA treatment.

Most people find their skin improves after around 20 treatments. It can remain clear for three to four months or sometimes longer. The number of treatments needed and how well they work is different for everybody. It also depends on the skin disease that you have.

## How good is PUVA compared to other sorts of phototherapy?

- For many skin conditions you are more likely to have a longer period where your skin condition disappears or improves.
- For many (but not all) conditions, PUVA works better than narrowband UVB (a different type of phototherapy).

### Be aware

PUVA treatment is usually better than sunlight for treating skin conditions. This is partly because the harmful and ineffective sunlight rays are filtered out.

## Will PUVA treatment cure my skin condition?

No. PUVA treatment will not cure your condition, but it can improve or clear it for a time and mean that your symptoms get better. You may need to have it again in the future if it has improved your condition.

## Are there any other treatments that I might be able to have instead of PUVA?

Your skin specialist thinks that PUVA is the best treatment for you. There may be other treatments that you could have. This depends on what condition you have.

Other treatments include:

- Narrowband UVB (NB-UVB). This involves standing in a phototherapy cabinet while a machine makes NB-UVB rays which reach your skin.
- Systemic medication (medicines that you take that work throughout your whole body). These are oral medications (medicines such as a tablet or liquid that you take by putting them in your mouth and swallowing them).
- Creams or ointments. These might be used alone or at the same time as PUVA treatment.
- Injected medicines.

### Be aware

We will usually only give you oral medications or injections if light treatment is not safe for you or we believe it will not work well for you.

Your skin specialist will explain other treatments you might have, or more information can be found on The Psoriasis Association website.

**Do** ask your skin specialist to tell you more about any of the treatments if you are not sure what they involve or whether they may be right for you.

## Asking for your consent

Before you have your treatment, we must tell you (inform you) why we think you need it. We will explain:

- What the benefits of having the treatment might be.
- What the risks of having the treatment might be.
- Whether there are any other treatments for your condition and how suitable they might be for you.
- What might happen if you decide not to have treatment.

We tell you these things to help you to decide whether the treatment is the best thing for you and whether you want to have it. The final decision about whether to have the treatment is yours.

Once you know about the treatment, we will ask you whether you agree to have it (consent to it). It is important that you understand what you are agreeing to. If you do not understand anything about the treatment do ask.

We will ask you to sign a consent form with your skin specialist and again at your pre-assessment when we see you to check how you are and whether it is safe for you to have the treatment.

## What do I need to know about parking at Southlands Hospital?

As you will need to come to the hospital often for your treatment and parking may be a concern for you. You do have to pay to park at the hospital, but you can park for free on the roads near the hospital.

# What things must I do, and not do, on the day of my treatment?

On the day of your treatment,

## Do not:

- **Wear perfumes, deodorants, aftershave, lotions, or any other cosmetics**, including make-up before your treatments (you can wear them afterwards).
  - These may have things in them which make your skin react more to light or contain sun-screen. This can mean you get coloured patches of skin when you have PUVA treatment. The patches can take months to fade.
  - Some medicines and ointments can also cause you to get these patches. For this reason, tell us if you start taking any new medicines while you are having your treatment.
- **Drink alcohol** before your treatment.
- **Put any creams or ointments onto your skin** before you go into the PUVA cabinet or sit at the PUVA light machine other than a moisturiser. Be aware:
  - You should use a water-based moisturiser such as E45 or Diprobase. You should put this on more than two hours before your treatment. Two hours before your treatment is best. Moisturiser can help your skin to take in the ultraviolet rays and help your treatment. Always use the same moisturiser.
- **Do not** use an oil-based moisturiser. These can cause your skin to burn and stop the PUVA treatment from working.
- If you are not sure which moisturisers are safe to use, ask one of the Phototherapy nurses.

## Do:

- Wear glasses straight after you take your psoralen tablets. You must wear them from the time you take the tablets until nightfall on the day of your treatment. You can wear your own



sunglasses or glasses with special UV filters. You can get these from an optician.

- **Be aware**, you must wear either of these types of glasses to protect your eyes from damage caused by UVA.
- **Remove any jewellery** or body piercings before your treatment.
- **Eat a small meal or snack** when taking the psoralen tablets 2 hours before treatment.
- **Always take psoralen tablets 2 hours before treatment** unless the phototherapy staff advise you differently.

## What should I do, and not do, during the whole period that I am having treatments?

During the whole period that you are having PUVA treatments

### Do not:

- **Get too much sunshine** on your skin even through window glass. This is so that you help to avoid getting a reaction which is like sunburn. Make sure you:
  - Cover up with loose fitting clothes with long sleeves and wear a hat. This is most important on sunny days and especially if you do not have much hair on your head.
  - Wear a sunscreen cream or lotion. It should have a sun protection factor (SPF) of at least 30 (50 is best) and have 4 or 5 stars on the bottle. This will protect you from UVB and UVA rays.
  - Re-apply your sunscreen often and put it on at least 20 minutes before you go outside. It is very important to re-apply sunscreen after you have been swimming or if you have been sweating a lot.
- **Sunbathe or use a sunbed.**
- **Get a new tattoo.**
- **Have any cosmetic treatments.**

## Do:

- **Tell us if you wish to or have had haircut** or if any of your skin that is not usually exposed to sunlight does become exposed for any reason.
- **Come to all of your appointments wearing clothes that cover all your body.** We advise that you wear a long-sleeved top, long trousers and shoes and socks both on your way to and from your appointment.
- Apply sunscreen of a SPF of at least 30 (50 is better) to any areas of your skin that are not covered by your clothes before you leave.

## What should I do when I arrive for my treatment?

Please sit in the dermatology waiting area. You do not need to check in at main reception. You will be called in when it is time for your appointment.

## Do I have to come for a pre-assessment any appointments before my course of treatments start?

Yes. You will need to come one appointment before your treatment starts.

This is a pre-assessment on a Wednesday afternoon.

An appointment letter with the date and time will be sent to you in the post. The pre-assessment is to check that it is safe for you to have UVA therapy and for you to be able to ask any questions and consent to treatment.

**Do bring your UV filtered sunglasses or glasses with you to your pre-assessment appointment.**

You may also be required to have a blood test prior to starting treatment.

## How do I get the psoralen medicine that I need to take before my treatments?

At your pre-assessment appointment we will give you a prescription for your psoralen tablets. You must take this to the Pharmacy at Worthing Hospital. They will contact you to tell you when you can collect your psoralen. Sometimes the Pharmacy will have to order your psoralen in. It can take up to a week to arrive.

## When will I start my treatments?

Once you have your psoralen tablets do contact the Phototherapy nurses. They will tell you when you can start your treatments.

### Be aware

Please arrive for all your future appointments at the time that we have given you.

**Do not** bring valuables to your appointments. We do not have lockers that you can keep them in.

## How long will my treatments take?

Your treatment will take around 15 to 30 minutes. This includes time for you to get undressed and dressed if you need to. The exact time that you will be in the treatment cabinet depends on things such as your skin type (how light or dark your skin is) and the skin condition that you have.

It may only take a few seconds to give you your first dose of PUVA. If you have not been harmed by this dose, your next dose will increase slightly. This means your treatments are likely to take longer over the course of your sessions.

We will explain this to you in more detail at your pre assessment and will check the amount of PUVA you get at each session.

## **Can I have my treatments if I am feeling unwell?**

**Do** tell a member the phototherapy team staff as soon as possible if you feel unwell on the day of your treatment. This includes having a fever (high temperature), feeling dizzy or feeling sick (nausea). It may not be safe for you to be in the treatment cabinet if you are feeling unwell.

## **Can I have my treatments if I am planning to be pregnant or breastfeeding or there is a chance that I could become pregnant during the time I am having treatments?**

No. You should not have PUVA treatment if you are pregnant or breastfeeding. You will need to take a pregnancy test before you start PUVA treatment. We will test all women of child-bearing age (with their consent) at their pre-assessment appointment to see if they are pregnant.

There is no evidence that PUVA can damage a baby while it is developing during pregnancy (while it is a foetus). To be sure that any developing baby cannot be harmed by PUVA we advise that if you may be pregnant you do not have PUVA until after your baby is born or we know that you are not pregnant.

**Do** tell us if you think are pregnant, planning a pregnancy or think that there is a chance that you could become pregnant during the time you will be having treatments, or breast feeding.

## What happens during my treatment?

The Phototherapy Nurse will call you from the waiting area when the treatment room is ready for you to use. **Be aware,** we do our best to keep to your appointment time, but sometimes there may be a delay. Please ask one of the nurses if you are concerned about your waiting time.

- The nurse will check your skin and ask you some questions before you start your treatment. Do tell your nurse if you have started taking any new medicines or using new creams since your last session. This includes things that you have bought from a pharmacy or other shop.
- We usually ask you to remove all your clothes. If you have areas of your skin that are not affected by your skin condition, we will ask you to keep these covered.
  - Men must wear dark underwear or cover their genitals with a dark sock or a jock-strap while they are in the treatment cabinet.
  - If you do wear underwear or clothing in the cabinet do make sure it covers the same areas on each visit. You can do this by wearing the same style.

### Be aware

If an area of your skin that has previously been covered during your treatments gets UVA rays on it, it may burn.

- Before you get into the treatment cabinet, we will give you goggles to protect your eyes. We will tell you how to stand in the cabinet to make sure that the UVA can get to the areas of your skin that need it.

- If you are having treatment sitting at the hand and foot machine rather than in a cabinet you can carry on wearing your UV filter sunglasses or glasses for the whole of the treatment.
- After we have worked out the dose of UVA that you need you will go into the cabinet and we will turn it on.

## How does having PUVA therapy feel?

The light inside the cabinet is bright and you may feel warm.

### Do:

- Close your eyes when you are in the cabinet and the UVA light is on.
- Tell us if the heat or the amount of time you have to stand up for is too much for you. We can put a fan on to cool you down if the heat gets too much for you.

## What happens at the end of each treatment session?

If you have been undressed for your treatment, you will get dressed. The nurse will arrange a time for your next treatment session with you. You can then go home.

## How often will I need to have treatment?

This depends on your skin condition. Most people have two treatments a week for 12 weeks so they have 24 treatments in total.

We do not do treatments on bank holiday Mondays. Sessions are added at the end of your treatment if you miss one because there is a bank holiday Monday in your treatment period. We still do treatments on Thursdays in weeks in which there is a Bank Holiday Monday.

## Be aware

This is an intensive course of treatment. Before you start treatment do make sure that you can commit to coming for all your treatment sessions. This treatment has better results if you come to all the sessions at the time when you are due to have them.

## What side effects could I get from having PUVA therapy?

As with most treatments there can be side effects from PUVA treatment. We will talk with you about what the side effects (complications) may be in more detail. They can include:

- Your skin can sometimes become itchy and dry.
- Some people can feel sick (nauseous) after they take the psoralen tablets. If this happens to you try taking your tablets in two batches. Leave a 30 minute gap between taking the first and second batch.
- Your skin condition could get worse for a short time
- You may get uneven colour or tanning of your skin.
- Your skin may burn. This can happen with UVA as it can with sunlight. We will try to avoid this, but some tanning and redness of your skin is likely. This may look different in black or brown skins. Burns may be mild to severe. Severe burns are unlikely but can cause redness, pain, and blistering.
- Some people can get polymorphic light eruption. This is an itchy rash due to sunlight. It is rare for people to get this.
- As with too much sun exposure, long term use of UVA (many months to years) may age your skin and increase your risk of developing skin cancer. This increased risk is very slight at first,

but increases after about 150 to 200 treatments. It is unusual for us to give patients more than this number of PUVA treatments.

- If you do not wear the protective goggles in the cabinet, there is a chance that you may get a sunburn like reaction to your eyes. This happens within a few hours after treatment. It may also increase the chance that you will get eye cataracts in the future.
- You may get cold sores due to UVA exposure if you have the cold sore (herpes simplex) virus. This happens to around one in thirty people. Tell the phototherapy nurse if you have had cold sores before and if you notice early signs of tingling or a painful lump developing on your lips.
- If you have rosacea or have had cold sores which, can be made worse by the sun, we will shield your face during treatment. We will also ask you to apply an SPF lip balm or block. You can buy this at any supermarket.

PUVA is often a good treatment for people with skin problems but may not be right for you. There may be many reasons for this including for example, if you have very fair skin or if your condition gets worse in the sunlight.

## How should I care for my skin after my treatment?

After your treatment you may get:

### Dry skin.

- You may want to apply your moisturiser or other creams and ointments after your treatment. You can do this straight after your treatment in your 30 minute appointment slot. Most people prefer to do this when they get home.
- PUVA can make your skin feel dry so you may find it more comfortable to apply moisturiser four to five times a day.



## **Redness** (this may appear darker in black or brown skin).

- If you get sunburn after your treatment, please treat your skin as you usually would after sunburn with regular moisturisers. It is usual to have slight redness from 8 to 24 hours after your treatment. This usually fades quickly and is not sore.

### **Be aware**

If you have bad sunburn or blistering after your treatment do contact the Dermatology office within office hours (Monday to Friday 9am to 4pm). Outside office hours contact a GP or go to Accident and Emergency.

**Do** tell the Phototherapy nurses if you have a skin reaction to your treatments so that we can adjust your dose of UVB if we need to.

## **Will I have any more appointments after my treatment sessions have finished (follow up appointments)?**

You will usually have a follow up with a doctor or nurse three months after your treatment, or sooner if you are having problems.

## **What happens if I need to cancel my appointment?**

It is vital that you phone us as soon as you know that you won't be able to get to your appointment. If you know in advance that you can't get to one of your appointments, let us know.

Please contact the Phototherapy Room. See the pages at the end of the leaflet for contact number. Leave a message if no answer.

If you have to cancel 2 or more of your appointments, we cannot guarantee you will have a full course of treatment. If you miss two appointments without contacting us it is hospital policy to discharge you.

# What should I do if I think I am going to be late for my appointment?

## Be aware

We may not be able to give you your treatment if you are more than 15 minutes late.

Do phone us if you think you are going to be more than 15 minutes late for your appointment. Leave a message if your call is not answered. This can help you to avoid having a wasted trip to the hospital if we are unable to fit in your appointment because you are late.

## Where can I find further information about my condition or PUVA?

**National Eczema Society**

<https://eczema.org/>

**The British Association of Dermatologists (sun awareness)**

<https://www.skinhealthinfo.org.uk/sun-awareness/>

**NHS Advice (sunburn)**

<https://www.nhs.uk/conditions/sunburn/>

**The Psoriasis Association**

<https://www.psoriasis-association.org.uk/>

**The British Association of Dermatologists PUVA patient information leaflet**

<https://www.bad.org.uk/pils/phototherapy-oral-puva/>

**The Vitiligo Society**

<https://vitiligosociety.org/>

# Who should I contact if I have any questions or concerns about my treatment after I have read this information?

If you have any questions or concerns about your treatment, please contact the Dermatology department.

## Dermatology nurses

Monday to Friday 9:00 am to 4:00 pm

**01903 205111 Ext. 83212**

In an emergency ask for ext. **01903 205111 Ext. 83607**

## Phototherapy room

Monday to Friday 9:00 am to 4:00 pm

**01903 205111 Ext. 83213**

## Dermatology secretaries

Monday to Friday 9:00 am to 4:30 pm

**01903 205111 Ext. 85080**

This leaflet is intended for patients receiving care  
in Southlands, St. Richard's and Worthing Hospitals.

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