

# Verteporfin and photodynamic therapy for central serous chorioretinopathy

This leaflet explains more about the use of verteporfin and photodynamic therapy (also called PDT) for the treatment of central serous chorioretinopathy (CSCR). It includes information about the benefits, risks and any alternatives, and what you can expect when you come to hospital.

If you have any further questions, please speak to a doctor or nurse caring for you.

## What is PDT?

Photodynamic therapy (PDT) with verteporfin is used in the treatment of central serous chorioretinopathy (CSCR). It involves giving you a drug called verteporfin (brand name Visudyne®) as an injection into a vein in your arm. The drug circulates through your body and is absorbed by the abnormal blood vessels in the back of your eye. A low energy laser is then directed at these vessels to activate the drug. Activated verteporfin slows down blood flow and allows the fluid leakage (CSCR) to settle.

## Why should I have PDT?

In CSCR, fluid leaks under the retina (the thin lining at the back of the eye that allows us to see) from a deeper layer of abnormally leaky blood vessels. For most patients this condition resolves all by itself within a few months, without needing treatment.

We recommend that you should have PDT because your CSCR has not cleared. About eight in 10 patients who undergo PDT will notice an improvement in their vision within two months of a single course of treatment. In some patients there is no effect following the first session of PDT, and a second and final course may be needed about three months later.

Some people may be worried by information available on the internet about verteporfin because it is also used to treat age-related macular degeneration. We are using this drug to treat your CSCR, and we do not think you have age-related macular degeneration.

## Taking an unlicensed medicine

Verteporfin is not licensed for the treatment of CSCR as the characteristics of your condition are quite rare and the large clinical trials needed to obtain a license are not possible. However, your clinical need cannot be met by medicines that are currently licensed, and small studies and our own experience have shown that verteporfin used with PDT may improve your condition. Although there is no guarantee of a successful outcome, we are hopeful that you will benefit from this treatment.

You are being offered this treatment because your current condition meets the very strict guidelines that we have in place for giving this drug.

The leaflet, **Unlicensed medicines – a guide for patients**, has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively you can call the pharmacy medicines helpline – contact details are at the end of this leaflet.

## What are the risks?

PDT with verteporfin therapy is not suitable for everyone. People who have a very rare condition called porphyria, those with severe liver problems and those with allergies to any of the ingredients of verteporfin should not receive it. Check with your ophthalmologist (eye doctor) or other healthcare professional if you think any of these apply to you.

One or two out of 100 people who undergo this procedure experience a decrease in vision in the first seven days after treatment. Some of these patients achieve a partial or full recovery. **If you experience substantial vision loss, you should contact your ophthalmologist or retinal specialist immediately (contact details are at the end of this leaflet).**

The most common side effects (reported by between one and three out of every 10 patients treated) are injection site reactions, nausea (feeling sick), temporary back pain during the injection, and changes in vision, including blurring. You should let the staff in the eye department know if you experience any of these problems during your appointment.

We have listed just the most common side effects here. On the day of your appointment, you will also be given a copy of the patient information leaflet produced by the manufacturer of verteporfin. This lists all reported side effects with the drug and the action to take if you experience any of them. If you have any questions or concerns about the side effects of verteporfin, you should discuss these with your doctor or call the Pharmacy Medicines Helpline (see the back page of this leaflet).

You should **avoid direct sunlight or bright indoor (halogen) light for two days following therapy with verteporfin**. However, this does not mean you need to stay completely in the dark. Exposure to normal indoor lighting will help your body to eliminate verteporfin more quickly.

If you need to go outdoors in daylight during this time, you must **cover all parts of your skin (including your head) and eyes by wearing protective clothing and dark glasses**.

## Are there any alternatives?

Most cases of CSCR resolve without needing any treatment in a period of a few months. If this does not happen and the leaking blood vessels are close to the centre of the back of the eye, PDT with verteporfin is recommended as other types of laser treatment may be harmful.

## How can I prepare for PDT?

You should read this information leaflet and contact the eye department before your appointment if you have any further questions or concerns. On the day of your appointment, be sure to bring sunglasses and clothes that protect your skin from sunlight (hat, scarf, long sleeves, trousers, gloves) for your journey home.

## **Giving my consent (permission)**

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

## **What happens during PDT?**

You will have your height and weight measured to calculate the correct dose of verteporfin. Your vision will be checked and drops to dilate your pupils before the treatment can be given. The verteporfin will be prepared and infused through a cannula (a small tube) inserted into a vein in your arm. The drug infusion takes 10 minutes. After that, you will be given the PDT treatment. Some anaesthetic drops will also be applied to the affected eye to numb its surface. A contact lens will be placed on the eye – this will help to keep the eye still and the eyelids out of the way, and will allow the doctor to see the area to be treated.

The doctor will tell you when the laser will start – you must keep still and concentrate on the red laser light. The PDT treatment will take 83 seconds.

## **Will I feel any pain?**

No, the procedure is pain-free.

## **What happens after PDT?**

The contact lens and cannula will be removed, and you will need to change into the clothes and sunglasses that you brought with you to protect your skin and eyes from sunlight on your journey home.

You will not be able to drive home after the treatment as the dilating drops can take two to three hours to wear off.

## **What do I need to do after I go home?**

You need to stay indoors with bright light sources, including halogen lights, switched off. Try to avoid direct sunlight – we recommend keeping curtains half-drawn. You can resume your usual physical activities but you should avoid watching TV or using a computer for the first day.

You can return to all normal activities after two days.

A dimming of vision is normal; this can last up to a month.

## **Will I have a follow-up appointment?**

A follow-up appointment will be arranged in the eye clinic six to eight weeks after the treatment to see if the treatment has worked. You may need a repeat treatment to be booked at a future date if there has been no improvement.

## Contact us

If you have any urgent questions or concerns about verteporfin and PDT, please contact the eye department on 020 7188 0161 (Monday to Friday, 9am to 5pm).

If you need to be seen urgently by an eye doctor; for example if you think you have a serious adverse reaction to verteporfin and PDT, you should attend the Eye Casualty Department (8.45am to 4pm, Monday to Friday). It is located in the Eye Department, South Wing, Stairwell C, St Thomas' Hospital.

Outside of these hours, go to your nearest A&E Department.

## 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 and Accessible 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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